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Learning as a patient:

What and how individuals want to learn when
preparing for surgery, and the
potential use of serious games in their
education

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Learning as a patient: What and how individuals want to learn when preparing for surgery, and the potential use of serious games in their education

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An introductory video-clip on the serious game is available at:
<https://vimeo.com/183277621/cba443e2ba>

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*To my mother,
who first introduced me to nursing*

*Pleasure is the state of being
brought about by what you
learn.
Learning is the process of
entering into the experience of this
kind of pleasure.
No pleasure, no learning.
No learning, no pleasure.*

Wang Ken, Song of Joy

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ABSTRACT

Introduction: Surgical patients need knowledge to participate in their own care and to engage in self-care behaviour in the perioperative period which is important for their recovery. Patient education facilitates such knowledge acquisition and several methods can be used to facilitate it, for example, face-to-face education and brochures or using information technology such as websites or computer games. Healthcare professionals have been slow to seize the possibilities that information technology has to offer within the field, including the use of serious games. To optimise patient education the information is needed on the patients' needs and preferences and what they think about the idea of using a serious game to learn about self-care.

Aim: The overall aims of this thesis were to describe the knowledge expectations of surgical patients, to describe how surgical patients want to learn, and to explore the potential use of serious games in patient education.

Methods: This thesis includes four studies that used both quantitative and qualitative data to describe aspects of patient learning in relation to surgery. Study I has a prospective and comparative design with survey data collected before surgery and before hospital discharge from 290 patients with osteoarthritis undergoing knee arthroplasty. Data was collected on fulfilment of knowledge expectations and related factors. Study II is a cross-sectional study in 104 patients with heart failure who had been scheduled for cardiac resynchronisation therapy (CRT) device implantation. Data was collected on knowledge expectations and related factors. In Study III, the perceptions of 13 surgical patients concerning novel and traditional methods to learn about postoperative pain management are explored in a qualitative interview study using content analysis. Study IV describes the development and evaluation of a serious game to learn about pain

management with the participation of 20 persons recruited from the public. The game was developed by an interdisciplinary team following a structured approach. Data on the efficacy and usability of the game was collected in one session using questionnaires, observations and interviews.

Results: Participants reported high knowledge expectations. Knowledge expectations were highest within the bio-physiological knowledge dimension on disease, treatment and complications and the functional dimension on how daily activities are affected, both of which include items on self-care. Most participants wanted to know about the possible complications related to the surgery procedure. In none of the knowledge dimensions the expectations of patients were fulfilled. Participants received most knowledge on the physical and functional issues and received least on the financial and social aspects of their illness. The main predictor of fulfilment of knowledge expectations was having access to knowledge in the hospital from doctors and nurses. Trust in the information source and participants' own motivation to learn shaped how they thought about different learning methods. Although the participants were open to using novel learning methods such as websites or games, they were also doubtful about their use and called for advice by healthcare professionals.

To develop a serious game with the goal to learn about pain management, theories of self-care and adult learning, evidence on the educational needs of patients about pain management and principles of gamification was found useful. The game character is a surgical patient just discharged home from hospital who needs to attend to daily activities while simultaneously managing postoperative pain with different strategies. Participants who evaluated a first version of the serious game improved their knowledge about pain medication and described the usability of the game as high. They were positive towards this new learning method and found it suitable for learning about pain management after surgery in spite of some technical obstacles.

Conclusions: Surgical patients have high knowledge expectations about all aspects of their upcoming surgery and although they prefer direct communication with healthcare professionals as a source of knowledge they might be open to trying using more novel methods such as games. Preliminary short-term results demonstrate that a serious game can help individuals to learn about pain management, and has the potential to improve knowledge. A careful introduction, recommendation, and support from healthcare professionals is needed for implementation of such a novel method in patient education.

Keywords: Education, knowledge expectations, learning, serious game, surgical patients

LIST OF PAPERS

This thesis is based on the following four papers, which will be referred to in the text by their Roman numerals.

- I. Brynja Ingadóttir, Åsa Johansson Stark, Helena Leino-Kilpi, Árún K. Sigurðardóttir, Kirsi Valkeapää, Mitra Unosson (2014) *The fulfilment of knowledge expectations during the perioperative period of patients undergoing knee arthroplasty - a Nordic perspective*. Journal of Clinical Nursing, 23 (19-20); 2896-2908.
- II. Brynja Ingadóttir, Ingela Thylén, Tiny Jaarsma (2015) *Knowledge expectations, self-care, and health complaints of heart failure patients scheduled for cardiac resynchronization therapy implantation*. Patient Preference and Adherence, 9; 913-21.
- III. Brynja Ingadóttir, Katrín Blöndal, Tiny Jaarsma, Ingela Thylén (2016) *Perceptions about traditional and novel methods to learn about postoperative pain management - a qualitative study*. Journal of Advanced Nursing 72; 2672-83.
- IV. Brynja Ingadóttir, Katrín Blöndal, David Thue, Ingela Thylén, Sigríður Zoëga, Tiny Jaarsma (2016) *Development, usability and efficacy of a postoperative pain management computer game* – Submitted manuscript.

ABBREVIATIONS

ANOVA	Analysis Of VAriance
AKS	Access to Knowledge Scale
BQ-II	Barriers Questionnaire II
CAD	Coronary artery disease
CRT	Cardiac resynchronisation therapy
CVD	Cardiovascular disease
EHFScBs-9	European Heart Failure Self-care Behavior Scale
EPE	Empowering patient education
HF	Heart failure
KEhp	Knowledge Expectations of hospital patients - scale
NYHA-class	New York Heart Association functional classification
NRS	Numeric Rating Scale
OA	Osteoarthritis
PAK-PPM	Patient Knowledge About Postoperative Pain Management questionnaire
PSS	Patient Satisfaction Scale
POP-MGS	Post-Operative Pain Management Game Survey
PRP	Post-Operative Recovery Profile
RKhp	Received Knowledge of hospital patients – scale

INTRODUCTION

Learning is a process that results in change in knowledge or behavior, and patients who enter the healthcare system for surgery expect to learn about issues related to their health and the upcoming procedure; thus, they have knowledge expectations. Patient education refers to all educational activities directed at patients.¹ It consists of the learning-teaching process where the patient's learning is assisted by the healthcare professional's teaching strategies and selected instructional materials.² The goal of patient education is to develop patients' competence and confidence in carrying out health behaviours which are consistent with their life plan.³ As part of the psychological preparation for surgery, patient education may be beneficial for surgical outcomes.⁴ Patient education is an ethical, professional and, in some countries, a legal obligation of healthcare professionals. Their duty is to guarantee access to evidence-based, quality knowledge and know how to support the learning of patients.⁵ This puts responsibility on nurses to actively participate in developing effective educational interventions in the fast growing populations of people who need to prepare for surgery, self-care, and care-giving of others, or who need to understand the basis for healthcare-related ethical decisions.³

Nowadays, surgical patients are admitted to hospital for scheduled surgery later and discharged home earlier than in the past⁶ and are expected to manage themselves what was formerly part of the care provided by professionals. For such self-care they need certain knowledge but studies indicate that surgical patients' knowledge needs are insufficiently fulfilled.^{7,8} The reasons for this are complex and there is a need for more effective theory- and evidence-based patient education.⁹ Future challenges within patient education lie both in the training of healthcare professionals and patients and the application of e-Health techniques.¹⁰

Adult learning theories can be useful in the development of patient education as they describe the conditions under which the processes of learning are optimised.⁹ Individual differences may call for different teaching strategies¹¹ but

interactivity, multi-sessions and multiple media have been found to promote effective patient education.¹² Face-to-face education, in conjunction with written material, has been the most widely used source of information for patients.² Simultaneously it gives cause to challenge the lack of diversity in educational practices, which have developed very slowly within healthcare.

Information technology has the potential to transform health and healthcare education, as a new vehicle to deliver educational programs and promote learning.¹³ Serious games are an example of this. These are computer games which are designed for educational purposes.¹⁴ Games on self-care for surgical patients are not available yet but studies show promising results on the efficacy of serious games within healthcare in general.¹⁵⁻¹⁷

This thesis explores different aspects of the patient as a learner, what knowledge patients perceive they need in relation to upcoming surgery, how they want to learn and the potential use of a serious game to help them learn about an important aspect of postoperative self-care, that is, pain management. Such knowledge is important in order to develop further patient education for surgical patients, both in regard to its content as well as the implementation of new teaching strategies.

BACKGROUND

Patients have great expectations for healthcare when they enter the healthcare system and whether or not those expectations are met determines how satisfied they will be.¹⁸ Patient expectations are predominantly referred to as ‘value expectations’, a term which encompasses patients’ hopes, desires or wishes concerning clinical events.¹⁹ Expectations may also include knowledge expectations, to receive information and learn about important issues related to own health and care. This thesis uses the concepts of adult learning, patient empowerment and self-care as conceptual standpoints, each of which will be further described in relevant sections of this chapter. The chapter will describe the different aspects of the patient as a learner from the perspective of adult learning and relevant aspects of the patient undergoing surgery from the perspective of peri-operative nursing.

The learning patient

When individuals become patients they may need new knowledge, skills or may have to reconsider their attitudes and behaviour, all of which can affect their health. Knowledge is also an important prerequisite for their empowerment, and is recognised as imperative for sustainable health systems.²⁰

Learning theories provide the conceptual standpoint to understand how people learn, and subsequently what strategies to use to enhance their learning.²¹ They are used in this thesis to guide the study design and the interpretation of the results as well as the design of a serious game. While several definitions exist, in this thesis, learning has been defined as “*a process that brings together cognitive, emotional and environmental*

influences and experiences for acquiring, enhancing or making changes in one's knowledge, skills, values and worldviews" (p. 277).²¹ Patient learning is affected by several factors such as patients' readiness and motivation to learn, level of wellness, psychosocial state, socioeconomic and cultural factors, as well as educational level including health literacy.² Learning can be supported by choosing appropriate instructional strategies and material. In this section a closer look will be taken at adult learning, empowerment of patients, and how different teaching methods can promote learning, with a special focus on serious games.

Adult learning

The adult learner has certain characteristics such as being autonomous and self-directed, and having prior experience and knowledge on which to build new knowledge. He/she is goal-oriented and wants to learn what is relevant and practical at any given time. Adults learn best when they perceive the need to know, and when their motivation is high.²²

The complexity of learning has been described in theories with five main orientations relevant to patient education: the *behaviourist*, *cognitivist*, *social cognitive*, *humanist*, and *constructivist* orientations, which will be further described below. Each has its different perspective on the learner, the learning process, the purpose of learning and the role of the educator, sources of motivation for learning, and how learning is transferred to real situations.^{21,23}

Behaviourism is a worldview that defines learning as a change in the behaviour of the learner, and holds that behaviour is shaped through environmental positive or negative reinforcement of the passive learner.²⁴ Behaviourism precedes the *cognitivist* worldview which focuses on exploring mental processes such as thinking, memory, knowing, and problem-solving. The learner is viewed as an information processor;

information comes in, is processed and leads to certain outcomes. Actions and changes in behaviour are consequences of the thinking of a rational human being and learning is defined as changes in knowledge, through discovery of knowledge and construction of meaning.²⁴ Social cognition, a perspective within cognitivism, reflects a constructivist orientation and highlights the influence of social factors on perception, thought, and motivation.²⁴ With humanism, learning is viewed as a personal act to fulfil one's potential. It assumes that people act with intentionality and values and its primary purpose is the development of self-actualized, autonomous people. The study of the self, motivation, and goals are areas of particular interest. Learning is student-centred and personalised and the educator is a facilitator of learning.²⁴ According to the experiential learning theory,²⁵ which belongs to the humanism paradigm, knowledge is created through the transformation of experience in the process of learning.²⁵ Through concrete experience and abstract conceptualization, experience is grasped and experience is transformed through reflective observation and active experimentation (the decision and problem-solving stage).²⁵ Constructivism is a worldview which posits that learning is an active, contextualized process of constructing knowledge rather than acquiring it. Learners use prior knowledge and experience and link these with new information to construct their own subjective representations of objective reality.²⁴

Behaviourist, cognitive, and social learning theories are usually applied in patient education within nursing practice²³ and this is manifested in the emphasis on measureable, learning objectives of changes in knowledge and behaviour.³ However, advances in learning theories within patient education are evident, and these are moving towards the constructivist perspective which defines learning as knowledge construction.³ The humanistic perspective, on the other hand, encourages

a patient-centred approach to care and has added much to the understanding of human motivation and emotions in the learning process.²³

The diversity of learning theories suggests the various external and internal factors that shape learning and determine how information is perceived, interpreted and remembered, and whether acquired knowledge will be used.²³ The theories are not mutually exclusive, but can operate together to explain different aspects and situations and multimodal approaches may indeed be the most effective in patient education. Theoretical assumptions about the learner vary between theories, from being passive to being active; thus, passive individuals may learn better with behaviourist approaches while cognitive and humanistic approaches may suit more active individuals. Other individual characteristics may also determine which approaches are more suitable, such as education, cognitive status or preferred modes of learning.²³ Such a person-centred approach to education is not only likely to facilitate learning but subsequently also to support patient empowerment.

Empowerment and the knowledgeable patient

Personal empowerment has been visualised as the new healthcare revolution,²⁶ and to increase the sustainability of present paradigms of care delivery, patient empowerment has become a key priority for policy makers.²⁷ Patient empowerment is conceived to be a process, an emergent state, or a participative behaviour and is recognised as the combination of ability, motivation and power opportunities. It is defined as: *“the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an*

opportunity for higher levels of power in their relationship with professionals” (p. 390).²⁷

Empowering Patient Education (EPE) is a theoretical perspective used in this thesis, with roots in the concept of empowerment and in social-psychological theories and constructive learning theory.^{28,29} EPE emphasises the right of patients to know about their health, health-related problems, treatment and care. Empowerment forms the basis for their health and self-care. Patient education is a nursing intervention aimed at improving patients’ knowledge level, as knowledge is the basic element of empowerment.³⁰

Empowering knowledge is composed of patient’s previous knowledge, knowledge expectations and received knowledge (which refers to when a patient has received available information and made it a part of his/her own knowledge base) and has six dimensions: bio-physiological, functional, experiential, ethical, social and financial knowledge (Figure 1). It is assumed that the closer received knowledge is to knowledge expectations, in other words when knowledge expectations are fulfilled, the stronger the potential patients have for empowerment.²⁹⁻³³

Figure 1 Six dimensions of empowering knowledge and examples of their content. Based on ^{28,29,33}

Patients have expressed rather low preferences for information and active involvement in their healthcare in some studies^{34,35} indicating lack of empowerment. Those patients who wanted to be involved in their care, on the other hand, received less knowledge than patients who did not want to be involved,^{35,36} which may reflect lack of appropriate responses on behalf of the healthcare system when patients have high knowledge expectations.

Studies show that surgical patients, independent of their type of surgery, generally have high knowledge expectations and that these expectations are not sufficiently fulfilled^{32,33,37,38} although some topics are better covered in patient education than others. Technological and bio-physiological aspects of care seem to be most expected by patients and best addressed by healthcare professionals.^{7,39} On the other hand, knowledge expectations of patients on experiential and ethical issues, and social and

financial issues are least fulfilled.^{32,33}

Women, younger people, people with higher educational level, the unemployed and chronically ill are described to have less fulfilled knowledge expectations^{33,40,41} or received knowledge³⁰ than their counterparts. The same is true for patients with low health literacy³⁷ and patients in a depressive state.⁴¹ Patients have also reported receiving insufficient information^{19,42-44} which may leave them feeling vulnerable.⁴² Furthermore, inconsistent or variable advice from different healthcare professionals or others leads to confusion and less confidence.⁴³

This evidence indicates that there is a room for improvement within patient educational practices, improvements that should focus on meeting the individual needs of patients and subsequently improve optimal patient-reported outcomes.

Patients not only expect to gain knowledge; they are entitled to be educated and they have a statutory right to information from healthcare professionals in some countries for example in Iceland,⁴⁵ Sweden⁴⁶ and Finland.⁴⁷ To educate patients is also an ethical duty of nurses.⁴⁸

It is recognised that if patients are knowledgeable and well informed this can improve the outcomes of their treatment. This is evident in recent clinical guidelines and scientific statements, for example about postoperative pain management,⁴⁹ preoperative assessment of the geriatric surgical patient⁵⁰ or care of patients receiving an implantable cardioverter defibrillator (ICD).⁵¹ Outcomes of patient education on surgery can be either patient-focused or economic. Patient-focused outcomes are for example experiential (anxiety and depression, fear), and cognitive (objective and subjective knowledge) or bio-physiological (pain intensity and pain control). Economic outcomes include healthcare cost, length of stay or need for further care.⁵²⁻⁵⁵ Heterogeneity and inadequate quality of many studies on patient education outcomes make evaluation of the

effectiveness of the education problematic.^{52,53,56} However, there is a growing body of evidence indicating that patient education can improve knowledge, postoperative pain, satisfaction with care, healthcare utilisation, and can reduce anxiety and fear and support behaviour change.^{4,52-55,57,58}

Promoting learning with appropriate methods

An important component of promoting the learning process is choosing appropriate instructional strategies and material. An instructional strategy is the overall plan of the education and involves one or more instructional methods to present content in the education. Examples of methods are face-to-face education, demonstration, gaming or self-instruction. Instructional materials are the vehicles to communicate information and include printed, demonstration and audio-visual media.^{2,59}

The effectiveness of different strategies may depend on whether the objectives of learning are to affect knowledge, skills or attitudes; as well as on the individual characteristics, knowledge expectations and health literacy of the learner.² A common and traditional strategy in patient education is using face-to-face verbal education as a method, which is supplemented with printed, written information. More novel approaches use information technology in the form of interactive websites, computer games or web-based applications.⁶⁰

a) Face-to-face education, including guidance of information available on the Internet which many patients expect to use as an information source⁶¹ is important and much appreciated by patients. Unfortunately, face-to-face encounters are under threat because of healthcare professionals' time restraints.⁶² The effectiveness of this method is sensitive to multiple factors from the patient's and provider's side.⁶²

Face-to-face education is not effective on its own and should be used in conjunction with other methods.⁶⁰

b) Written material, especially when tailored to patients' needs, can be effective in patient education⁶⁰ but its use requires correct timing and satisfactory readability and it has to correspond to the patient's knowledge level⁵³ and health literacy. The general quality of written material, including content and instructiveness, is frequently inadequate, whether delivered on paper^{39,53,63} or via websites,⁶⁴ and interventions using written material show mixed results.⁵⁵

c) Computer technology can be an effective teaching strategy to improve patient knowledge and satisfaction, and to decrease anxiety⁶⁰ provided that such technology has a proper design, implementation and integration process.⁶⁵ A meta-analysis which compared Web-based interventions to non-Web-based interventions showed improved outcomes, both in health-related knowledge and behaviour.⁶⁶ Web-based interventions accessed during recovery at home after surgery are most effective when they are interactive and allow patients to navigate the online system on their own.⁶⁷

Reviews on the outcomes of patient education for surgical patients support practice which uses combined media, individualises the content, offers multiple sessions, provides the education on a one-on-one basis and includes the caregiver.^{12,55,56}

Available evidence is scarce on the effectiveness of more specific computer-based methods such as serious games for adults.⁶⁰

Serious games

The first computer games came on the market in the 1970s⁶⁸ and they have been studied increasingly in recent years as a medium of learning. "Serious

games” refers to games that are designed with education in mind, either for learning or training to affect knowledge, attitudes or behaviour.¹⁴ In this thesis the use of the concept is limited to serious computer games. Although no agreement exists on the definition of serious games, there is a consensus that a serious game should have a learning objective, be engaging, interactive and have some game element.⁶⁹ Theoretically, games have qualities which can support learning. They have features which are consistent with the principles of adult learning i.e. the potential for creating positive emotions, supporting problem-solving, encouraging active participation, using previous experience, and providing continuous feedback, all which can stimulate intrinsic motivation.^{70,71}

The use of serious games in healthcare has been tested with the goal of improving self-care in diabetes, asthma, cancer and Warfarin use, improving diet, pain, mobility, lifestyle and other behavioural changes, as well as health-related knowledge.^{14-17,72} Although inconclusive as yet, many studies have reported positive outcomes. However, methodological problems and differences in learning goals and definitions of outcomes call for larger studies and randomized controlled trials to test the effect on knowledge and self-care behaviour in this new field within patient education. No games were found which address the self-care of surgical patients.

The learning theories guiding serious game design have been divided into three generations.⁷³ The first generation of theories relied heavily on behaviourism with a typical feature that learning occurs through conditioning with rewards provided for the correct response to the stimuli. This theory failed to explain the thought process behind behaviour which gave rise to the second generation where cognitivism was utilised alongside constructivism in serious games and text, pictures and sounds were used to support learning, problem-solving and the application of previous

experience and knowledge. With cognitivism the learner became the centre of attention along with the learning content, settings, and differences between learners. According to constructivism, learners learn best when building their own understanding of the content by interacting with it. The goal in the game became to immerse the learner in a virtual world similar to the real world and allow learning to take place in a natural way. The third generation of theories uses constructionism as a successor and extension of constructivism where the crucial factor is that by thinking hard about the learning content and the best ways to convey it to others, and by explaining it to others, the learning is reinforced. Experiential learning theory is connected to constructionism and widely used in serious games where the player learns by doing (seeing or hearing).^{69,73}

The surgical patient

This section will describe the surgical context for the learning patient. The patient populations represented in this thesis will be introduced and the concept of self-care, with special focus on postoperative pain management and recovery will be described.

Surgery is a developed and successful medical treatment for many diseases. There have been impressive advances within the surgical speciality, both medical and technological as well as in postoperative care. This has changed both the characteristics of healthcare systems and patients' experiences. Examples of the changes within healthcare systems include shorter hospitalization^{74,75} and an increased proportion of day surgery which is approaching 70% of all surgery performed.⁷⁶ Shorter hospitalisation is often achievable after implementation of an Enhanced Recovery after Surgery (ERAS®) approach to patient management which

utilises evidence-based and structured surgical pathways in which patient education, patient involvement and collaboration are fundamental for optimal outcomes.⁷⁷ For patients, the advances in surgical treatment and postoperative care have in many cases resulted in less discomfort and faster recovery but more treatment options mean more decision-making for patients. Simultaneously, the expectations on patients to participate in their care and self-care, for example regarding pain management, have increased.

Perioperative nursing specialises in the nursing care of patients during the surgical process.⁷⁸ The perioperative period starts when a decision has been made on surgery and it ends when the patient has an achieved optimal level of postsurgical function.⁷⁸ Nursing researchers have increasingly been studying the impact of the changing surgical environment, the experience of patients after discharge in their postoperative recovery, how it can be supported and how practice must be adapted to this new reality. Patients have emphasised the importance of pre-admission contact, provision of relevant, specific education and information, improving communication skills, and involving carers throughout the perioperative period.⁷⁹ They, and their carers have reported difficulties in caring for themselves or their loved ones after day surgery and expressed the desire for better information and to obtain professional support after being discharged home.⁷⁹⁻⁸¹ This evidence raises concern about the responsibility of providers to prepare patients sufficiently for the self-care expected of them.

Patients undergoing surgery for common conditions

In this thesis, patients undergoing different types of surgery and with different underlying diseases are included. Data were collected from patients undergoing surgery for osteoarthritis (OA), heart failure (HF) and

cardiovascular diseases (CVD). These patients may at first sight look diverse, mainly because of their different medical diagnosis and, what healthcare professionals may refer to as ‘major’ and ‘minor’ surgeries. Conversely, all the patients (I - III) had a chronic disease in common which is debilitating and decreasing their quality-of-life and requires substantial self-care. The patients undergoing surgery as described in this thesis have several things in common but there are also some disease/surgery specific aspects to be considered, which will be presented first.

OA is one of the ten most disabling conditions, and HF and CVD, including coronary artery disease (CAD) are among the most prevalent conditions in the population aged over 70 in developed countries.⁸² They have a high level of co-occurrence and share common risk factors.⁸³ To improve quality-of-life, joint arthroplasty, coronary artery bypass surgery and cardiac resynchronisation therapy (CRT) pacemaker implantation are common surgical procedures offered to patients with OA, CAD and HF, respectively.

Patients with OA suffer from debilitating pain and impaired mobility causing loss of physical functioning. It is estimated that 18% of women and 10% of men aged over 60 have symptomatic OA.⁸² The prevalence of hip and knee replacement within the countries of Organization for Economic Cooperation and Development (OECD) is 161 and 121 per 100.000 population, respectively.⁸⁴ The prevalence is increasing with age and the secular trend indicates a rise in prevalence over time, with hip replacement increasing by 35% and knee replacement nearly doubled between the years 2000 and 2013.⁸⁴

Patients undergoing surgery for the CRT pacemaker implantation, HF patients, were recruited. HF is a complex syndrome which is caused by failure of the heart to deliver sufficient levels of oxygen to the body, causing symptoms like shortness of breath, exercise intolerance, fatigue

and ankle swelling.⁸⁵ HF is common, with a prevalence of ~1-2% in the population.⁸⁵ CRT is a medical management of HF symptoms which helps selected patients with HF who have systolic dysfunction (ejection fraction <35) and ventricular dyssynchrony. The treatment can reduce mortality and morbidity and increase patient's quality-of-life by improving hemodynamic in the body.⁸⁶ The treatment is an implantation of a device, a biventricular pacemaker with or without a defibrillator and requires a minimal surgical procedure and short hospitalisation. The estimated need for a CRT device is 400 implants/million inhabitants/year.⁸⁶ There is a 10% risk of complications and around 20% of patients do not respond to the treatment.⁸⁷ The educational needs of CRT patients have not been studied before.

During the perioperative period both basic and specific self-care is required of all surgical patients. For those who have a chronic illness, like patients with OA and HF, such self-care requirements are added to the usual self-care in their chronic illness.

Self-care

Performing specific self-care may require new knowledge and skills, adjustment in daily activities and in some cases re-evaluation of values, preferences and lifestyle. The Middle-Range Theory of Self-care in Chronic Illness⁸⁸ provides a conceptual standpoint to understand self-care. It has been used in this thesis to describe and to explain the concept of self-care within surgical care⁸⁹ (Figure 2) and to guide the design of the serious game (IV).

Self-care, according to the theory, is defined as a *“process of maintaining health through health promoting practices and managing illness”* and includes three key concepts: self-care maintenance

(behaviour), self-care monitoring (process) and self-care management (response); these are the core of self-care itself, or the behaviours and processes used by patients.⁸⁸

Figure 2 Self-care of surgical patients

Post-operative recovery and pain

After surgery the patient goes through ‘postoperative recovery’ a concept which has been defined as an *“energy requiring process of returning to normality and wholeness”* and is achieved by regaining control of physical, psychological, social and habitual function.⁹⁰ During recovery, the patient experiences uncomfortable symptoms, impaired function and disruption of daily life. The recovery process is completed when the patient reaches a preoperative level of independence/dependency in activities of daily living and an optimum level of psychological wellbeing.^{90,91} Common and severe symptoms in postoperative recovery are pain and fatigue, and emotions such as depression, anger and anxiety are also common. They may be

related to the fulfilment of patient expectations on the outcome of surgery.⁹⁰

Despite advances in the management of pain, the prevalence of postoperative pain in hospitals remains high with 82-90% of patients reporting pain in the past 24 hours.⁹²⁻⁹⁴ Pain is also common after hospital discharge with 75% of patients reporting pain, and of those, 80% rate their pain as moderate or severe.⁹⁵ A recent study demonstrated high prevalence of moderate to severe pain after cardiac surgery, insufficient analgesic administration and the patients were discharged from hospital with unrelieved pain and a potential risk for further postoperative complications.⁹⁶ Pain has negative effects on both the psychological and physiological wellbeing of patients, and increases the risk for chronic postoperative pain.⁹⁷ Effective pain management is therefore very important for recovery after surgery.

Sufficient education and access to information is the prerequisite for the self-management of complex symptoms such as postoperative pain. Patients need to understand why managing pain is important and how they can be active participants in their own treatment.^{93,98} Patients want information on how to treat their pain after being discharged, what to do if the treatment is insufficient, what side-effects of medications to expect and how to treat those side-effects.⁹⁹ Quality of recovery at day four has been found to be associated with the perceived usefulness of preoperative education in same day surgery patients,¹⁰⁰ and patients undergoing knee arthroplasty with fulfilled knowledge expectations had a better quality of recovery than those with unfulfilled ones.¹⁰¹

Rationale for this thesis

Patient education is one of the core components of nursing practice and in hospitals nurses are commonly responsible for its formal organisation and the development of methods and material used in the education. The importance of patient empowerment for self-care, decision making and treatment adherence is increasingly recognised as being necessary for patients' quality-of-life and other optimal healthcare outcomes. To become empowered, patients need knowledge.

Within surgical care there is a growing body of evidence on the importance of patient education. However, patients' needs for knowledge are more complex, multi-dimensional and individual than healthcare professionals may have realised and those needs are not being fulfilled. This can affect postoperative recovery, self-care and satisfaction with care. Therefore, more research is needed on the different aspects of knowledge expectations of surgical patients, what issues they want to learn about, how their knowledge expectations are formed, what the related factors are and how their learning can best be supported. The potentials of computer-based education are of special interest in that context.

The Internet may have replaced face-to-face education provided by healthcare professionals as the most common and important information resource for patients. Furthermore, information technology offers new potential in the design and delivery of patient education which may become valuable addition to the present educational strategies as the traditional face-to-face education and written information material have severe drawbacks in practice. One of the novelties that come with information technology is the serious game. Promising evidence is slowly emerging on the efficacy of these games but more research is needed, both on the patient perspective towards this way of learning and how feasible it

is to integrate such games into patient education for surgical patients. Finally, another challenge facing healthcare is the transferability of knowledge and how providers can support patients in making use of the information they are provided with.

Therefore, the goal of this thesis is to obtain knowledge and deeper understanding of the following components of patient education; the knowledge expectations of different groups of surgical patients, the patient perspective towards learning with different methods, and the potential of using serious games in patient education.

AIMS

The overall aim of the thesis was to describe the knowledge expectations of surgical patients, to describe how surgical patients want to learn and to explore the potential of a serious game in patient education.

The specific aims were:

Study I: To describe the possible differences between knowledge expectations and received knowledge of patients undergoing elective knee arthroplasty in Iceland, Sweden and Finland and also to determine the relationship between such a difference and both background factors and patient satisfaction with care.

Study II: To describe what knowledge heart failure patients expect to receive before undergoing CRT implantation, to describe their self-care and health complaints, and to explore the relationship between knowledge expectations and self-care, health complaints, and background factors.

Study III: To explore the perceptions of surgical patients about traditional and novel methods of learning about post-operative pain management.

Study IV: To describe the development of a computer game for surgical patients about post-operative pain management and to evaluate the usability, user experience and efficacy of the game.

METHODS

Design

Data for the thesis was collected in four separate studies, two quantitative studies, one qualitative study and one development and evaluation study.

Study I is part of a larger European research project, Empowering Surgical Orthopaedic Patients through Education (ESOPTE), in which seven European countries are participating. The study followed patients undergoing joint (hip and knee) arthroplasty up to six months after their surgery.¹⁰²

Study II is part of a larger research project, Patient Education and Expected Knowledge (PEEK), a prospective, follow-up study of patients with HF undergoing CRT pacemaker implantation. The aim of the research project was to assess patient-reported outcomes and their relationship with knowledge expectations. It followed patients for up to one year after their CRT pacemaker implantation but data used in this thesis was collected before the implantation.

Study III is a qualitative study using interviews with surgical patients. The study was designed to explore the patient's perspective of different methods to learn about self-care and was part of preparing the intervention described in Study IV.

Study IV presents the development and evaluation of a serious game about surgical postoperative pain management with the participation of people recruited from the public.

An overview of the design, participants, data collection and analysis used in the four studies is shown below (Table 1).

Table 1 Overview of the designs and methods in Studies I-IV

	<i>Study I</i>	<i>Study II</i>	<i>Study III</i>	<i>Study IV</i>
Design	Prospective, follow-up survey	Cross-sectional survey	Qualitative interview study	Development and evaluation study
Data collection period	2009-2011 Before surgery and at hospital discharge	2012-2014 Before surgery	2013-2014 7-30 days after hospital discharge	2015-2016 Before, during and immediately after playing the game
Participants and country	290 patients with OA undergoing knee arthroplasty Iceland Sweden Finland	104 patients with HF undergoing CRT device implantation Iceland Sweden	13 patients with OA or CVD undergoing arthroplasty or cardiac surgery Iceland	20 persons recruited from the general public Iceland
Data collection method ¹	Self-reported questionnaire	Self-reported questionnaire and medical record	Semi-structured interviews	Self-reported questionnaire, observation, semi-structured interviews
Data analysis	Descriptive and inferential statistics, linear regression	Descriptive and inferential statistics, logistic regression	Descriptive statistics Content analysis	Descriptive statistics Content analysis

¹The measures are presented in Table 4

Abbreviations: CRT Cardiac Resynchronisation Therapy; CVD Cardiacvascular disease; HF Heart Failure; OA Osteoarthritis

Participants, sample size, inclusion criteria, setting and procedures

Participants

Participants included in the thesis were surgical patients (I - III) and people visualising a scenario where they were having a surgery (IV). They came from Finland (I), Sweden (I - II) and Iceland (I - IV), three Nordic countries which have similar, well-developed hospital services and healthcare systems which rank among the top ten in Europe.¹⁰³

The sample in Studies I and II was a probability sample. All patients undergoing elective knee replacement (I) or CRT device implantation (II) in consecutive order in the participating centres and who fulfilled inclusion criteria were invited to join the study. The sample in Studies III and IV was a non-probability sample; purposive in Study III and a convenience sample in Study IV.¹⁰⁴

Sample size

A power calculation was performed to determine the desired sample size for the whole research project of which Study I is a part of, i.e., to detect differences in KEhp and RKhp including both hip and knee arthroplasty patients in the seven participating countries. Accordingly, a sample size of 1540 was required for the study, or 220 per country with a power level of 0.90 and a 0.80 difference of mean scores with 0.95 standard deviation within groups at the significance level of 0.01.¹⁰⁵ For Study II a sample size of 100 patients was deemed sufficient based on the rule of thumb that a reasonable sample size is 50 to assess relationships (correlations and regression) and a cell size of 30 provides 80% power when measuring group differences.¹⁰⁶ New participants were recruited in Study III until no

new data emerged, which was established after the preliminary analysis of 11 interviews. The findings were further confirmed after recruitment of two more participants. In Study IV the sample size was based on recommended sample size (N=20) when collecting quantitative usability metrics in the evaluation of interactive products.¹⁰⁷

Inclusion criteria

The inclusion criteria required participants to be 18 years or older (upper limit 70 years in Study IV), have no documented cognitive impairment, be able to fill out questionnaires (I - IV), understand Icelandic (I - IV) / Swedish (I - II) / Finnish (I), undergo elective arthroplasty for OA (I, III), cardiac surgery (III) or elective CRT for HF (II) and to be familiar with using a computer (IV).

Setting and procedures

Procedure of recruitment

Studies I and II were multi-centre and international studies. In Study I patients were recruited from seven hospitals, three in Iceland, two in Sweden and two in Finland during 2009-2011. The Swedish and Finnish hospitals were chosen by convenience while all Icelandic hospitals performing knee replacement were included. In Study II patients were recruited from the only Icelandic hospital performing CRT implantation and from five out of the 30 hospitals in Sweden that perform CRT implantation,¹⁰⁸ during 2012-2014. Patients in Study III were recruited from three surgical wards in an Icelandic university hospital during a 10-month period in 2013-2014, and participants in Study IV were recruited via Facebook advertisement and a researcher network in Iceland during one month in 2015-2016.

Educational preparation of patients

Before being scheduled for the elective surgery and before hospital admission, patients had been referred to and met medical specialists in orthopaedics (I, III) or cardiology (II - III). Educational preparation varies between procedures, centres and countries but standard, face-to-face education is provided by the medical specialists and by nurses at outpatient or pre-admission clinics. The education includes distribution of printed, written material, usually prepared by staff at the hospital (I - III) but sometimes published by the device industry (II) or patient organisations. Patients with OA also receive education from physiotherapists and, in some cases, occupational therapists.

Procedure of data collection

For Studies I and II, information about the prospective patients undergoing surgery was collected from the hospitals and appointed study nurses at each centre were responsible for sending out the study package, which included an information letter, a consent form, a questionnaire and a prepaid return envelope. The second questionnaire in Study I was distributed before the patient's hospital discharge by the study nurses. For Study III, eligible patients were approached by specially appointed staff nurses at least one week after hospital discharge. Patients who were interested and gave their oral consent were contacted by the author and introduced to the study. An information letter and a consent form were sent by e-mail to those interested in participation and an appointment made for the interview at a place of their choice. For study IV, the people who saw the recruitment advertisement on Facebook and were interested in participating contacted the author. They received an information letter and a consent form via e-mail and an appointment was made at a convenient time. Data was collected before, during and immediately after the participants played the game, during one session in a hospital office.

Development of a serious game

Study IV describes the development and evaluation of a serious game for patients to learn about postoperative pain management. In planning the intervention the principles of the Intervention Mapping protocol¹⁰⁹ and guidelines on how to develop more effective games and how to conduct research on them¹¹⁰ were used. A first prototype was used in the development process, which took place from January to December 2015 and involved three phases (Figure 3): (i) Preparation, (ii) Define learning goals and (iii) Game design.

Figure 3 An overview of the game development

The game was developed and evaluated in an Icelandic setting. A multi-professional team of computer scientists, game and graphic designers, nurse researchers and clinical nurse specialists, with expertise in nursing care of surgical patients, patient education and pain management, collaborated in the design and development of the game. The nurse researchers defined the clinical problem and its context as part of their work within the patient education development. The computer scientists with expertise in game design, narratives and computer science

contributed by realising those ideas in a usable game to educate patients about pain management. Adult learning theories and a theory on self-care guided the development of the game. The user perspective had previously been explored in Study III. After defining the learning goals, the team met regularly for brainstorming sessions to ensure that the educational components of the game idea were accurately translated into the design of the game and to develop solutions for the interface, continuous feedback system and the after-action review. Such sessions were repeated, and the design of the game refined until a prototype was ready to be evaluated. Table 2 describes the characteristics of the game and Table 3 shows its components. The game's interface is presented in Figure 4.

Figure 4 The interface of the serious game

Table 2 Characteristics of the serious game

<i>Characteristics</i>	
Health topic	Self-care of surgical patients: pain management
Target players	Adults having surgery
Timing	Introduced as part of preparation before surgery and used again after surgery as part of discharge education
Game idea	A serious game aimed to educate about facts concerning pain medication and strategies for effective pain management in the home environment after hospital discharge
Guiding theoretical perspectives	Middle-range theory of chronic illness, adjusted for surgical patients, ⁸⁸ Androgogy, ²² Experiential learning ²⁵
Type of game	Realistic, educational, simulation
Intended outcome(s)	<p>Knowledge about four commonly used pain medication after surgery (name, dosage, effects, possible side effects)</p> <p>Knowledge about non-pharmacological strategies for pain relief</p> <p>Knowledge about effective strategies for pain relief</p> <p>Problem solving skills to control pain intensity</p> <p>Self-care pain monitoring skills</p> <p>Self-care pain management skills</p> <p>Facilitating attitude towards pain management</p>
Levels of play	One game session consists of three games, each covers a 24-hour day (from 9 am to 9 am next day) with separate goals, and ends with an after-action review
User interface and platform	<p>11,5" touch screen on a tablet computer (Android) allows for easy use in the hospital environment</p> <p>Interface</p> <ul style="list-style-type: none"> - Numeric rating scale (NRS) for pain - Pain medication board - Button for showing goal - Board for daily tasks
Avatar	Human who can walk around the house, use a shower and toilet, cook food, watch television, use computer, rest on a sofa, lie in bed
Virtual environment (setting)	A house with a living room, bedroom, kitchen, bathroom
Software	Unity3d (© 2016 Unity Technologies)
Estimated play time	30 minutes

Table 3 Components of the serious game

Introduction & Instructions	Presentation of the game scenario and context of the game. Presentation of the user interface (Figure 4).
Story	The player controls the actions of a virtual human character who has recently been discharged from the hospital following surgery. By making different decisions (choosing between 4 different pain medications, performing basic household tasks, and taking time to rest) about the character's daily activities players can observe how their decisions influence the character's recovery.
Activity - goals	Three games in each game session, three specific goals to accomplish: Day 1: "Take as little pain medication as possible" Day 2: "Keep pain severity under 3 on a NRS regardless of side-effects from pain medication" Day 3: "Keep pain severity under 5 the whole day"
Activity – tasks to complete in each game	Players are required to have the character complete a set of common daily tasks, including self-care (e.g. bathing) and household tasks (e.g. cooking meal). A list of household tasks appears on the right of the game's main screen (e.g., "wash the dishes"), and players can complete each task by tapping on its related object in the house (e.g., the kitchen sink). Players can also move the character around the house by tapping on the floor at the desired new position.
NRS for pain	Players see the character's pain represented as a vertical meter ranging from 0 to 10 (NRS).
Side-effects	Side effects are represented by both unique character animations and descriptive icons that appear below the pain meter.
Character commentary (text bubbles)	These expose the character's (fictional) "inner monologue" via occasional text bubbles that appear in the game (e.g., "Maybe I should call Mom today..."). They appear both at random (for fun) and as a feedback to pain management or information on pain status along with information on NRS.
Medicine cabinet	Above the pain meter is an icon that represents the character's medication supply, and tapping this icon reveals a new screen that shows the four available medications along with descriptions of their function and side effects. This allows players to choose which medications the character should take and how much of each (if any) at each time.
Help button	Occasionally and randomly pain becomes unmanageable ($NRS \geq 8$). Such situation represents what can happen in real life. The help button gives contact with a healthcare provider and after the consultation, pain intensity decreases to 5.
After-action review	At the end of each day a graphical overview appears on the player's performance. This is a tool to use in a debriefing with a healthcare professional. A table appears, informing how many tablets of each pain medication were taken. A graph presents the intensity of pain over 24 hours, what measures were taken to relieve pain (marked with green) and what activities impaired with pain relief (marked red). Separate dots on the graph represent intake of pain medication and if/when and which side-effects appeared.

Data collection

Data was collected with self-reported questionnaires (I - IV), semi-structured interviews (III - IV), non-participant observation (IV) and from hospital records (II).

Background and characteristics of the participants

Data was collected on age, sex, education, employment (I - IV), including history of employment within healthcare or social services (I - II), marital status, NYHA functional class, medication (II), chronic illness/comorbidities (I - III) and type of surgery (I - III). Participants also answered questions about where they had received information in relation to their surgery (II - III), their use of computers, mobile/smart-phones and computer games (III - IV).

Health literacy was assessed with three screening questions; 1. "How often do you have someone help you read hospital materials?" and 2. "How often do you have problems learning about your medical condition because of difficulty understanding written information?" [response options never/occasionally/sometimes/often/always]; and 3. "How confident are you filling out medical forms by yourself?" [response options extremely/quite a bit/somewhat/a little bit/not at all] (III - IV). Health literacy scores are reported as the proportion (%) of people who answer "often" or "always" in questions 1 or 2; and who answer "extremely" or "quite a bit" in question 3. Each of these questions has been found to be an effective screening test for inadequate health literacy in a preoperative patient population in the United Statesⁱⁱⁱ but was used for the first time in Iceland in these studies.

Instruments

Table 4 presents an overview of the instruments which were used in the thesis and their reliability (internal consistency) as measured in the four studies. The instruments Knowledge Expectations of hospital patients scale (KEhp), Received Knowledge of hospital patients scale (RKhp) and Access to Knowledge Scale (AKS) had previously been translated from Finnish to English. The researchers in Iceland and Sweden were responsible for having the English version translated to Icelandic/Swedish and then back-translated to English. The English version of KEhp and RKhp had not been used previously.¹⁰⁵ Other instruments which were not already available were translated as required from the original language into Icelandic/Swedish/Finnish and then back-translated.¹⁰⁴ All the instruments were piloted before being administered to study participants. No, or only minor changes to each instrument were needed after the pilot testing.

To test the internal consistency of the instruments, Cronbach's α coefficient was used to calculate the reliability coefficient of all instruments except the PAK-PPM where the Kuder-Richardson (KR-20) coefficient was chosen as that data is dichotomous.¹⁰⁴ A value of ≥ 0.70 for Cronbach's α was considered acceptable.¹⁰⁴ The reliability coefficients are presented in Table 4.

Table 4 Overview of the instruments used in Studies I - IV

<i>Study</i>	<i>Variable</i>	<i>Instrument subscales</i>	<i>No. of items</i>	<i>Score</i>	<i>Internal consist.^a</i>
I, II IV	Knowledge expectations	Knowledge Expectations of hospital patients scale	40	1-4	0.94- 0.98
		<i>Bio-physiological</i>	8		0.91
		<i>Functional</i>	8		0.91
		<i>Experiential</i>	3		0.83
		<i>Ethical</i>	9		0.91
		<i>Social</i>	6		0.87
		<i>Financial</i>	6		0.93
I	Received knowledge	Received Knowledge of hospital patients scale	40	1-4	0.97
I	Patient satisfaction with care	Patient Satisfaction Scale	11	1-4	0.96
I	Contact and information from HP	Access to Knowledge Scale^c	8	1-4	0.84
I	Preferences for information and behavioural control	Krantz Health Opinion Survey	16		
		<i>Preferences for information</i>	7	1-7	0.50
		<i>Behavioural control</i>	9	1-9	0.65
II	Self-care	European Heart Failure Self-care Behavior scale-9	9	1-5	0.71
		<i>Consultation</i>	4		0.82
II	Health complaints	Postoperative Recovery Profile^b	19	1-4	0.91
IV	Attitude towards pain management	Barriers Questionnaire-II^b	27	0-5	0.91
		<i>Harmful effects</i>	12		
		<i>Physiological effects</i>	6		
		<i>Communication</i>	6		
		<i>Fatalism</i>	3		
IV	Usability	Post-Operative Pain Management Game Survey^b	12	0-5	0.83
		<i>Ease of use</i>	8		
		<i>Usefulness</i>	4		
IV	Knowledge	Patient Knowledge about Postoperative Pain Management questionnaire^c	15	0-15	0.68 (KR-20)
IV	Usability	AttrakDiff2	28		0.75
		<i>Pragmatic quality</i>	7		
		<i>Hedonic quality (identification)</i>	7		
		<i>Hedonic quality (stimulation)</i>	7		
		<i>Attractiveness</i>	7		

^aCronbach's alpha coefficients except for PAK-PPM = Kuder-Richardson reliability coefficient (KR-20), as measured in this thesis; ^bAdjusted for use in this thesis; ^cNot validated earlier; HP Healthcare professionals; Roman numerals I-IV refer to Studies I-IV

Knowledge expectations and received knowledge

The *Knowledge Expectations of hospital patients* and *Received Knowledge of hospital patients* scales (KEhp and RKhp, ©Leino-Kilpi, Salanterä, Hölttä, 1993) (I, II, IV) are parallel 40 items scales, divided into six subscales of empowering knowledge, i.e. bio-physiological, functional, experiential, ethical, social, and financial (Figure 1). Responses are ranked on a four-point scale (1 = fully disagree, 4 = fully agree, 0 = not applicable). Patient expectations and received knowledge is the average score for the total scale and subscales of the instruments, with the possible range of 1-4 where higher scores reflect higher knowledge expectations or received knowledge. Fulfilment of knowledge expectations is calculated by subtracting expected knowledge from received knowledge with the possible range of -3 to +3. Patients with no or a positive difference were defined as experiencing fulfilled knowledge expectations, if the difference had a negative value the expectations were unfulfilled. The instruments have previously been tested and their content validated, and they have shown good internal consistency in their original Finnish versions.^{30,32,33,38} Cronbach's alpha in the thesis was 0.94-0.98 for the total scales and 0.83-0.93 for the subscales (Table 4).

Satisfaction with care

The *Patient Satisfaction Scale* (PSS) (I) is a validated instrument used to measure satisfaction with hospital care after surgery.¹¹² Patient satisfaction is the mean score of the included 11 items, with possible scores 1-4 (1 = very dissatisfied, 4 = very satisfied) and higher scores indicate more satisfaction. The instrument has been used in different European countries and has good psychometric properties.¹¹³ Cronbach's alpha in this thesis was 0.96.

Access to knowledge

The *Access to Knowledge Scale* (AKS) (I) consists of eight statements derived from different theoretical components of the Good Nursing Care-Scale (72 items).³¹ The statements cover matters such as how well the medical staff and nurses could answer the patient's questions and justify their actions, keep patients and significant others up to date with care related matters and provide patients with knowledge. Responses are ranked on a four-point scale (1 = fully disagree to 4 = fully agree). Access to knowledge is the mean score of included items of the AKS with possible range of 1-4. Higher scores reflect better access to knowledge. AKS has not been used or validated as a scale before but in this study showed acceptable internal consistency (Cronbach's α coefficients 0.84) and item-item Spearman's correlation coefficient ranged between 0.32 - 0.69.

Preferences for information and behavioural control

The *Krantz Health Opinion Survey* (KHOS) (I) is a 16 item validated instrument with two subscales; KHOS-I (7 statements) which describe patients' activities to seek health-related information and KHOS-B (9 statements) describes preferences for participation and control over one's own healthcare. The respondents rate the answers with a binary scale (yes/no). Sum variables of preferences are sums of individual item codes, possible maximum scores are 7/16 for KHOS-I and 9/16 for KHOS-B, with higher scores indicating higher levels of preferences for health-related information and higher preferences for control over own care.¹¹⁴ KHOS is reported to have satisfactory face and content validity, internal consistency and test-retest reliability.^{36,114,115} Cronbach's alpha in the thesis was 0.50-0.64.

Self-care

The *European Heart Failure Self-care Behavior Scale – 9* (EHFScS-9) (II) is a well validated and reliable instrument developed to measure the behaviours that HF patients perform to maintain life, healthy functioning and wellbeing. Responses are ranked on a five-point scale (1 = fully agree, 5 = fully disagree). Possible scores are 9-45 and scores can be standardized to 0-100 after which higher scores indicate better self-care.¹¹⁶ Consulting behaviour dimension of the scale consists of four items and measures how often the patient calls a doctor or nurse in case of symptoms.¹¹⁷ Cronbach's alpha in this thesis was 0.71.

Health complaints

The *Post-Operative Recovery Scale* (PRP) (II) is designed to evaluate the progress of postoperative recovery and the long-term follow up of possible effects of interventions during recovery. This 19 item instrument consists of five dimensions which measure the prevalence and severity of problems with physical symptoms, physical functions, psychological, social and activity and its validity and high reliability has been confirmed^{91,118} The instrument was adjusted in this thesis in order to get a baseline status of health complaints in patients before surgery by adjusting wording. Health complaints are the average score for a total scale of the instrument with a possible range of 1-4 (1 = severe, 4 = none). Higher scores reflect lower problems. The number of health complaints was calculated by summing the health complaints that scored 1-3.

Attitude towards pain management

The *Barriers Questionnaire II* is designed to evaluate attitudes and possible barriers of people towards pain management. It is a previously validated 27 items instrument divided into four subscales. Participants rate the extent

to which they agree with each item on a six-point scale anchored with 0 (do not agree at all) and 5 (agree very much). Higher scores reflect higher barriers to pain management.¹¹⁹ The instrument was adjusted before being used in this thesis (IV) such that the five items with referrals to ‘cancer pain’ were changed to ‘surgical pain’. Cronbach’s alpha in this thesis was 0.91.

Ease of use and usefulness of a serious game

A previously validated instrument based on variables identified in the Technology Acceptance Model¹²⁰ was modified before use in this thesis (IV) and is hereafter referred to as The Post-Operative Pain Management Game Survey (POP-MGS). It was modified such that the items referred to the pain management game instead of the exergaming software which the original version was used to assess. Its 12 items measure perceived ease of use and usefulness of the simulation software and interface design. Responses are ranked on a six-point scale (0 = strongly disagree and 5 = strongly agree), higher scores reflect higher usefulness and ease of use. Cronbach’s alpha in this thesis was 0.83.

Knowledge on pain management

The *Patient Knowledge About Postoperative Pain Management* questionnaire (PAK-PPM) is a 15 items instrument, specially designed for the purpose of Study IV, by three nurse researchers with expertise in the care of surgical patients and pain management. The multiple-choice questions are based on literature review and clinical expertise of the authors and reflect the content of the serious game as well. The questionnaire consists of five components of postoperative pain management: pain after surgery (2 items), common pain medications and their dosages (7 items), pain management strategies (2 items), side-effects

of the treatment (2 items), and what to do if problems arise (2 items). Each item offers six response alternatives to choose from; one of them is the correct answer, the remaining five (including “do not know”) are handled as incorrect answers. Scores are graded according to proportion of correct answers. The face validity of the PAK-PPM was established in advance by administering it to 5 individuals, not included in this study and resulting in minor adjustment and addition of one response option (“do not know”). Kuder-Richardson reliability coefficient (KR-20) was 0.68.

Usability of a serious game

The *AttrakDiff 2* instrument was used to evaluate the serious game (IV). It consists of 28 seven-step items whose poles are opposite adjectives and each set is ordered into a scale of intensity. Each of the middle values of an item group creates a scale value for pragmatic quality (PQ), hedonic quality (HQ; including HQ-Identification and HQ-Stimulation) and attractiveness (ATT).¹²¹ Possible scores are -3 to +3. A high HQI score implies a high perceived capability of communicating identity to others, a high HQS score implies a high degree of perceived novelty, stimulation and challenge. A high PQ score primarily implies high usability.¹²² The Icelandic version of the *AttrakDiff2* has previously been validated.¹²³ Cronbach’s alpha in this thesis was 0.75.

Interviews

In Studies III and IV, data was collected through face-to-face semi-structured interviews by the author who is a clinical nurse specialist in surgical care and experienced in qualitative interviewing.

Study III

The semi-structured interviews were used to explore the participants' perceptions of traditional and novel methods to learn about postoperative pain management. The interviews started by presenting a vignette to the participants and they were asked to describe their preferences about how to learn about pain management during discharge after surgery. The participants were asked to 'think aloud'¹²⁴ while prioritising the different methods from 1 to 4 and thereafter to reflect on their choices. Probing questions were used to obtain further details and as new experiences unfolded these were used in subsequent interviews as the basis of probing questions.

The vignette consisted of a scenario of a planned postoperative discharge education on pain management and was followed with an example of four different methods which could be used for such education: face-to-face verbal education with a nurse, written education from a brochure, or education via a website or a computer game. The vignette was guided by the principle that a constructed scenario can facilitate a discussion about something unknown.^{42,125}

The interview guide was based on theories and principles of adult learning and learning styles,²¹ a literature review and the clinical expertise of the authors. It was validated separately by three surgical nurses and two teachers and pilot tested with three patients who had recently had surgery. Each pilot interview was approximately 1 hour long, gave rich data and resulted in some minor adjustments to the interview guide and the addition of one media option (the website) to the vignette. The pilot interviews were not included in the study.

The interviews lasted between 40-77 minutes (median 56 minutes) per participant; they were digitally audio-recorded and transcribed verbatim.

Study IV

Semi-structured interviews with open-ended questions were used to gain a deeper understanding of the participants' perspective of the usability and efficacy of the serious game and to validate and clarify results¹²⁶ from the survey they had answered earlier.

The participants were first asked questions about *knowledge acquisition* (Please describe what this game was about. How did you make decisions in the game? Did you learn anything new and if so, what?); followed by questions about *usability* (What do you think about this method of learning about pain management? What was easy and not so easy while playing? How did you perceive the game character (the avatar)? How can the game be improved?) Probing questions were used to obtain further details. The interviews ended with questions about the participants' ideas for further improvements of the game. The interviews were video-recorded and lasted between eight and 15 minutes.

Observations

Observation was used for data collection on the usability of the game (IV). Each playing session (N=20) was video-recorded and observed directly by the author and one other nurse researcher. A camera was installed in the room, aimed at the tablet computer screen and managed by the observers via a telephone application. During the observation, brief field notes were taken on any incidents or problems which came up during playing. The observers were available to provide assistance if needed but otherwise did not interfere with the playing session. The recordings were transferred to a computer, labelled and prepared for analysis. Each playing session took on average 34 (range 24 – 45) minutes.

Data analysis

Quantitative data

For all studies (I - IV), descriptive statistics were used to describe the study variables and population. Continuous data such as age and scale scores were described by means [with standard deviations (SD)] or medians [with interquartile range (IQR)] depending on the distribution of data. Categorical data, such as education, employment and health literacy were described by frequencies and percentages (%).

Continuous variables were compared between groups by the Student's *t*-test, or One-way Analysis of variance (ANOVA) for normally distributed data, and the Mann-Whitney *U*-test or Kruskal Wallis test for skewed data. A paired *t*-test was used to analyse differences within groups.

Categorical variables were compared between groups with Pearson's χ^2 test and Fisher's exact test. Correlation analyses were conducted to describe the bivariate relationship between study variables, with Spearman's correlation coefficient for ordinal variables and non-normally distributed continuous variables and Pearson's correlation coefficient for continuous variables.

Questionnaires from patients who had answered at least 50% of the items in KEhp/RKhp were included in the analysis. Missing data ranged between 0-13% and missing values were not replaced.

The level of statistical significance was set at <0.05 and the software package IBM SPSS-Statistics, versions 20-23, was used for data analysis (IBM Corp., Armonk, NY, USA).

Study I

A paired sample *t*-test was used to examine the difference between RKhp and KEhp (i.e. knowledge difference) within participants. Knowledge

differences between two or more independent groups were tested with an independent sample t-test or one-way ANOVA. The Bonferroni method was used for post-hoc comparisons. As a first step to explore factors associated with the knowledge difference, a bivariate correlational analysis was performed, using Spearman's rho correlation coefficient. The variables were selected based on prior empirical evidence or theoretical assumptions hypothesised to be associated with the fulfilment of knowledge expectations. In the correlation analysis the scales AKS, PSS and KHOS were used as well as age, education level, employment, previous employment within healthcare or social services, sex, if this was the patient's first arthroplasty or not and country. Based on the results of the bivariate correlation, variables that were to be used as predictors in the regression analysis were determined if the p-value was <0.05 . Next, a stepwise, multiple, linear regression was performed. The independent variables were AKS and KHOS-I (continuous variables) and the categorical variables employment history within healthcare or social services (yes/no), first joint arthroplasty (yes/no) and country (Iceland/Sweden/Finland). No variables indicated problems with multicollinearity as the variance inflation factor (VIF) was <2 in all models of the regression analysis.¹²⁷ The model was linear and the residuals were normally distributed.

Study II

Variables of the total scale and the six subscales of KEhp were computed and then further dichotomised into low and high expectations with the median value as a cut-off point as the data were not normally distributed. A total scale of health complaints was computed and then further dichotomised into no complaints (score 4) and health complaints (scores 1-3). Background variables on education and employment were dichotomised for further analysis into low and high education, retired vs employed and

living alone vs living with others. A background variable on the number of information sources which the patient had used was computed.

A binary logistic regression analysis employing the enter method was used to model the association between high (coded as 1) or low (coded as 0) knowledge expectations as the dependent variable. Significantly related factors in the univariate analysis were entered as independent variables. A significant level of $p < 0.10$ was required to enter an independent variable into the multivariate model. The included variables were age and health complaints. Excluded variables were gender, education, employment and self-care (EHFScBS-9). The fitness of the model was acceptable, with a p-value of 0.374 (Hosmer and Lemeshow), and (pseudo) $R^2 = 0.0120$ (Nagelkerke).

Study IV

Scores of PAK-PPM were computed as sum scores of correct answers and then standardised from 0 to 10 ($[\text{score} * 10]/15$, every item was given an equal weight). A paired sample t-test was used to compare knowledge scores for the PAK-PPM total scale before and after testing the game.

The observed and video-recorded playing sessions were analysed by measuring how long it took the participants to play the game, counting how often they asked for help and how often they ran into problems while playing the game.

Qualitative data

The semi-structured interviews (III - IV) were analysed with a content analysis approach.¹²⁸

Study III

In Study III, inductive, qualitative¹²⁹ and both manifest and latent analysis approaches¹³⁰ were used. The transcribed interviews were carefully read to obtain a sense of the whole and then text about participants' responses to the research questions was identified and brought together into one text. This text was then divided into meaning units that were condensed and then abstracted and labelled with a code, continually considering the context. The codes were compared with regard to similarities and differences and then preliminary categories and sub-categories were created as groups of expressed manifest and latent content. To validate the analysis process, a second researcher (a clinical nurse specialist in surgical care and a researcher) separately carried out the same process and both researchers compared their analyses and revised and discussed them until consensus was reached.¹³³ Finally, the creation of sub-categories and categories was validated by the third researcher through discussions of the findings (researcher triangulation).¹⁰⁴ An example of a quotation, code, sub-category and a category is given in Table 5.

Table 5 Example of the analysis process used for semi-structured interviews

<i>Quotation</i>	<i>Code</i>	<i>Sub-Category</i>	<i>Category</i>
"One isn't so involved and I just don't know what to ask about. When you go there (hospital) you are so nervous, and if you have prepared questions you forget them"	Impaired ability to learn due to surgery and/or postoperative treatment	Managing an impaired cognition	Being motivated to learn

Study IV

In Study IV, the qualitative data from the video-recorded observations (free text notes) and interviews (open-ended questions) was analysed with deductive directed content analysis¹²⁶ in order to validate the results of the survey on usability and efficacy (knowledge acquisition). These two concepts were decided on as categories beforehand. The two researchers took notes while watching and listening to the video-recordings from the observations and interviews and categorised them as either 'usability' or 'knowledge'. The content was discussed between the researchers and a summary of the interview with each participant was written.

Ethical considerations

Ethical codes and principles provide guidelines on research involving human subjects. Every researcher must evaluate these for him/herself by using 'reflective ethical inquiry', i.e. constant self-questioning through the research process regarding the possible consequences of intervening in other people's lives.¹³¹

The studies in this thesis were designed and conducted in accordance with the principles of human research outlined in the Helsinki Declaration.¹³² A detailed research protocol was prepared for each study and approved by the relevant research ethics committees in Iceland, Sweden and Finland, as follows:

Study I: Iceland 09-084-SI, Sweden Dnr. M69-09,

Finland ETMK: 102/180/2008

Study II: Iceland 12-029-SI, Sweden Dnr. 2012/120-31

Study III: Iceland 43/2013

Study IV: Iceland VSN-15-164

Risks and burden of participation and the vulnerability of patients were considered in the studies' design, including the inclusion criteria. An ethical consideration was how burdensome it would be for patients to answer the questionnaires. Answering a long survey may tire participants who are old or unwell, and this was particularly of concern in Study I. Patients answered the second questionnaire shortly after their surgery and within the potentially stressful environment of the hospital. The choice of instruments and number of questions was therefore carefully considered and patients could ask for help with filling out the questionnaire. To reduce the burden for patients in Study III the inclusion criteria were that they had been at home after hospital discharge, for at least a week before being interviewed but less than a month. The interviews (III) were guided by respect and sensitivity to the participants, and awareness that they were describing their recent experiences as patients in a vulnerable state after surgery.

Confidentiality implies that any personal data that could lead to the identification of the participant will not be reported.¹³³ Questionnaires, interview recordings and the video recordings were coded, secured in places inaccessible to others, and will ultimately be destroyed. Personal information was stored separately from the data. No information that could violate confidentiality was disclosed in the presentation of results. Special caution is needed in small societies like Iceland, where the risk of recognising a person should not be underestimated.

Privacy was secured by inviting the participants in Study III to choose where the interview took place, for example at their home or at the hospital, and offices which were available for Study III and used in Study IV were carefully chosen in a quiet part of the hospital where the risk of disruption was minimised.

All participants received information in writing about the study, where their voluntary participation was emphasised and other requirements stated in the Declaration of Helsinki were stated. A signed consent form was collected from all participants.

Participants in Study IV were given a gift token for their contribution, but other incentives were not used. The researchers were not involved in the care of the participants (I - III).

All stakeholders in the design, implementation and evaluation of serious games for healthcare have a professional, ethical responsibility to integrate ethico-legal aspects into the game in an appropriate and context-specific manner. This includes adherence to core educational principles and capturing real world uncertainties.¹³⁴ The challenge in the design of the game about pain management was to ensure that the educational content was evidence based and its presentation clear in order to prevent misunderstanding. This was considered throughout the whole design process.

RESULTS

The overall aims of this thesis were to describe the knowledge expectations of surgical patients, to describe how they want to learn, and to explore the potential of a serious game in patient education. In this chapter the main results concerning what patients want to learn, how patients want to learn (with different methods), and the evaluation of a serious game are presented, integrating results from the different studies.

Background and characteristics of participants

The participants in this thesis were 290 patients undergoing knee arthroplasty (I), 104 patients with HF scheduled for CRT pacemaker implantations (II), 13 surgical patients who recently had arthroplasty or open cardiac surgery (III) and 20 healthy people recruited from the public (IV). The age of the participants ranged between 24 and 90 and there was an equal distribution between men and women in all studies except Study II where 21% were women. The participants reported no or minimum health literacy problems (III - IV) (Table 6).

Table 6 Background characteristics of the participants in Studies I - IV

	<i>Study 1</i> <i>N=290</i>	<i>Study 2</i> <i>N=104</i>	<i>Study 3</i> <i>N=13</i>	<i>Study 4</i> <i>N=20</i>
Age (yrs) mean (SD)	67 (9.3)	70 (10.0)	61 (11.5)	48 (14.0)
Women	53%	21%	54%	55%
Education level*				
<i>Basic (≤ 9 years)</i>	54%	44%	23%	10%
<i>College level</i>	19%	28%	69%	20%
<i>Academic degree</i>	13%	27%	8%	70%
<i>Other</i>	7%	1%	-	-
Employment*				
<i>Employed</i>	31%	20%	77%	85%
<i>Retired</i>	59%	72%	23%	10%
<i>Other</i>	8%	8%	-	5%
Has worked in healthcare or social services (yes)	26%	18%	-	-
Health literacy scores	-	-		
<i>Problems learning about medical condition</i>			0%	11%
<i>Receive help with reading material</i>			0%	21%
<i>Confidence in filling out medical forms</i>			85%	85%
Type of surgery	KA	CRT	JA (7) CS (6)	- -

* Values may not add up to 100% due to missing data

Abbreviations: CRT Cardiac Resynchronization Therapy implantation; CS Cardiac Surgery; JA Joint arthroplasty; KA Knee arthroplasty

What patients want to learn

In this section of the results data on knowledge expectations (I, II, IV), received knowledge (I), fulfilment of knowledge expectations (I) and

factors related to both knowledge expectations and their fulfilment (I, II) will be reported.

Knowledge expectations

The knowledge expectations of the participants (I, II, IV) ranged between (median) 3.55 (IQR 0.40) and 3.75 (IQR 0.51) on a scale with a theoretical range of 1-4. The highest knowledge expectations before surgery, in all three studies, concerned bio-physiological issues (e.g., disease, treatment and possible complications) and functional issues (e.g., diet, rest, mobility or hygiene), and both subscales included several items on self-care activities. The ranking of other knowledge dimensions varied.

Table 7 Expected knowledge of participants in Studies I, II and IV

	<i>Study I</i> (N=290) <i>OA (knee)</i> <i>patients</i>	<i>Study II</i> (N=104) <i>CRT</i> <i>patients</i>	<i>Study IV</i> (N=20) <i>Healthy</i> <i>people</i>
KEhp scale			
	Median (IQR)		
<i>Total scale</i>	3.75 (0.51)	3.68 (0.50)	3.55 (0.40)
<i>Subscale</i>			
Biophysiological	4.00 (0.25)	4.00 (0.13)	4.00 (0.00)
Functional	3.88 (0.44)	3.88 (0.38)	4.00 (0.34)
Experiential	3.67 (1.00)	3.67 (1.00)	3.67 (0.67)
Ethical	3.78 (0.63)	3.57 (0.50)	3.22 (0.53)
Social	3.50 (0.83)	3.50 (0.83)	3.17 (0.67)
Financial	3.83 (0.80)	3.67 (1.00)	3.42 (1.17)

Scores range between 1-4; higher scores indicate high expectations.

Abbreviations: CRT, cardiac resynchronisation therapy; IQR, interquartile range; KEhp, Knowledge Expectations of hospital patients; OA, osteoarthritis

The highest knowledge expectation of patients in the bio-physiological dimension, was to learn about possible complications of the treatment (I, II). Table 8 presents the highest knowledge expectations in each subscale, of the participants in Studies I and II.

Table 8 Highest knowledge expectations – top item(s) per subscale *

KEhp scale	Item	Study I N=290	Study II N=104
Subscale			
	<i>“I expect knowledge on...”</i>	<i>% of patients who fully agree</i>	<i>% of patients who fully agree</i>
Biophysiological	Possible complications	90%	91%
Functional	Physical exercises	92%	84%
	When I can wash/shower /sauna	87%	89%
Experiential	What feelings illness and its treatment may cause	63%	63%
Ethical	Own responsibility for success of care	84%	80%
Social	Who informs my next of kin	80%	71%
	Where to get further treatment if needed	76%	79%
Financial	Rehabilitation cost	72%	62%
	Medication cost	69%	68%

* One item is included per subscale if it was the same in both studies, two items show the top two items in each study.

Abbreviations: KEhp, Knowledge Expectations of hospital patients scale.

Received knowledge and fulfilment of knowledge expectations

Received knowledge was assessed by OA patients after surgery (I). Received knowledge was lower than expected knowledge, both in the total scale and all subscales ($p < 0.001$) and the difference was smallest within the

bio-physiological and functional dimension and greatest within the financial dimension (Table 9).

Table 9 The difference between received and expected knowledge in patients undergoing knee arthroplasty for osteoarthritis (N=290)

<i>Study I (N=290)</i>	<i>Received Knowledge RKhp</i>	<i>Expected knowledge KEhp</i>	<i>Difference between received and expected knowledge</i>	<i>p-value*</i>
	Mean (SD)			
<i>Total scale</i>	3.03 (0.70)	3.62 (0.42)	-0.59 (0.73)	<0.001
<i>Subscale</i>				
Biophysiological	3.52 (0.63)	3.79 (0.45)	-0.27 (0.65)	<0.001
Functional	3.40 (0.61)	3.68 (0.50)	-0.28 (0.62)	<0.001
Experiential	2.75 (1.00)	3.45 (0.66)	-0.71 (1.09)	<0.001
Ethical	2.84 (0.63)	3.53 (0.57)	-0.69 (0.93)	<0.001
Social	2.60 (0.97)	3.40 (0.61)	-0.80 (1.02)	<0.001
Financial	2.30 (1.01)	3.52 (0.69)	-1.22 (1.15)	<0.001

*Paired t-test between RKhp and KEhp; Scores range between 1-4; higher scores indicate high expectations or high received knowledge.

Abbreviations: KEhp, Knowledge Expectations of hospital patients scale; RKhp, Received Knowledge of hospital patients scale.

Factors related to knowledge expectations and their fulfilment

Knowledge expectations were positively correlated with age (I, II). Older patients had higher expectations as measured both in the total scale as well as in the ethical, social and financial subscales ($p < 0.05$). Patients who had worked within healthcare or social services had higher knowledge expectations compared to their counterparts in Study I ($p < 0.05$) but this difference was not found in Study II. Women in Study I had higher knowledge expectations than men ($p < 0.05$) but such a difference was not

found in Study II. The more information resources patients with heart failure had used, the fewer knowledge expectations they had, and patients who had received information from the cardiac outpatient clinic had fewer knowledge expectations than their counterparts (Table 10).

Table 10 Factors related to knowledge expectations

Study	Factor	KEhp**						
		Total scale	Subscales					
			BIO	FUN	EXP	ETH	SOC	FIN
I	Age (r_s)	0.169*	0.180*	0.153*	0.078	0.185*	0.181*	0.179*
II	Age (r_s)	0.203*	0.162	0.102	0.281*	0.233*	0.253*	0.248*
I	Sex ^a	p=0.041*	p=0.026*	p=0.147	p=0.019*	p=0.043*	p=0.045*	p=0.074
I	Worked in health-care ^a	p=0.010*	p=0.211	p=0.095	p=0.007*	p=0.159	p=0.065	p=0.049*
II	Number of information resources (r_s)**	-0.262*	-0.164	-0.283*	-0.182	-0.237*	-0.281*	-0.276*
II	Information from COC staff ^a	p=0.001*	p=0.404	0.030*	0.002*	0.004*	0.004*	<0.001*

*p<0.05, **Additional analysis performed for thesis from Study I, ^aMann Whitney U test

Abbreviations: BIO, biophysiological; FUN, functional; EXP, experiential; ETH, ethical; SOC, social; FIN, financial; COC Cardiac Outpatient Clinic

The difference between expected and received knowledge, i.e. the fulfilment of knowledge expectations (I) was positively correlated with access to knowledge ($r_s=0.435$, $p<0.001$) but negatively correlated with information preferences ($r_s=-0.164$, $p=0.008$) and patient satisfaction ($r_s=-0.396$, $p<0.001$). The knowledge difference was more negative for Swedish patients, those who were having their first arthroplasty ($p<0.05$) and patients who had worked within healthcare or social services ($p<0.05$) than

for their counterparts. In the multivariate analysis, access to knowledge from healthcare professionals explained 30% of the variance in the difference between received and expected knowledge ($R^2=0.33$, $F= 41.390$, $df=3.252$, $p<0.001$). Information preferences (1%) and work experience within health or social care (2%) were also contributing factors in the model.

Learning with different methods

In this section of the results data on how patients want to learn, their perceptions of different learning methods and methods they used will be reported (II - IV).

Preferred methods of learning

Participants ranked their preferences for both traditional (face-to-face and written material) and novel (websites and serious games) methods to learn about postoperative self-care (pain management) and described their perceptions of each method (III). They were all familiar with face-to-face education and written material in the form of brochures but less so with using websites and no one had experience of using games for health information purposes. The face-to-face education was preferred by most participants, followed by written material, websites and games. Participants emphasised the importance of using more than one method as each has its advantages and disadvantages, and these are context-bound.

From the qualitative analysis it was found that there were several factors that underlay the preferences for certain educational methods such as: (1) 'Trusting the source', sub-categorised into 'Being familiar with the method' and 'Having own prejudgments'; and (2) 'Being motivated to

learn', sub-categorised into 'Managing an impaired cognition' and 'Aspiring for increased knowledge'.

Trusting the source

Confidence in the specific source was found to be pivotal, and was strongly based on communication with healthcare professionals, their skills, approval and recommendations.

Being familiar with the method

Being familiar with the method influenced the creation of trust. Familiarity with methods, even though they were not without their flaws, was important. Therefore, face-to-face education was preferred by most participants and written material was appreciated, as it was a resource published by the hospital and therefore trusted, even though it did not necessarily meet the knowledge expectations of participants.

Having own prejudgments

Own prejudgments were frequently mentioned by participants when they described trusting or not trusting the novel methods of websites or serious games. They were familiar with the Internet and used it in daily life but health-related issues were not included in their common use. Prejudgment and scepticism were expressed about searching for and using web-based information as well as using a serious game.

Being motivated to learn

The use of more than one medium was perceived as motivating and as meeting an emerging need for knowledge which arose after surgery and after discharge home. Verbal instructions could provide an overview of what to expect while the written material was perceived as a tool to help

remember practical things. A game might be helpful to visualise unanticipated problems or scenarios while the Internet could be referred to when new problems arose or deeper understanding was required.

Managing an impaired cognition

The participants described how they learned to manage their pain by trial and error, guided by the [mostly] sporadic verbal and written instructions they perceived they had received on hospital discharge. Motivation to seek information through other media, for example the Internet, increased when they perceived the need to learn more because the trial and error method was not sufficient. However, motivation decreased when cognition was impaired because of anxiety, pain, fatigue and side-effects of medication. Impaired cognition caused slow thinking, forgetfulness and lack of concentration, which subsequently impaired the participants' capability and interest in learning.

Aspiring for increased knowledge

Managing pain and other self-care activities was facilitated by verbal and written instructions from healthcare professionals and supported by previous experience. It was common to experience insufficient pain relief and/or to be prescribed two or three different medications which the participants said they had little knowledge about. In spite of that, few participants perceived a need to actively strive to learn more about pain management and seek knowledge beyond trial and error, or experiential knowledge. Those who did would search for information on the Internet but no-one had received recommendations from healthcare professionals about helpful websites, although they would have appreciated it.

The use and perceptions of different learning methods

The patients with HF (II) received, on average, information from two resources before surgery (median 2.00, range 0-5). Information was most commonly received from physicians or nurses at the outpatient cardiac clinic (79%) and from brochures (49%), followed by the Internet (18%), staff at the hospital ward or health care centre (9%), and family or friends (8%), while one patient (1%) had received information from a patient organisation and 4% from other resources. The participants in Study III had all received information from staff at the admission clinic and from brochures, while nine out of 13 had themselves looked for information on the Internet and six had used friends or family as an information source.

Face-to-face education

Face-to-face education was preferred by most participants (9 out of 13) in Study III and they described its advantages and disadvantages. The advantage of face-to-face education was reported to be the personal contact that gives the possibility of being actively involved by asking questions and raising one's own concerns. The patients trusted healthcare professionals to choose and deliver relevant and correct information. The described disadvantages of this method were that not all healthcare professionals were perceived to be skilled educators and the face-to-face education was not always helpful or supported learning. Reflecting back, the participants realised that some important topics such as discharge information on pain management, including the difference between different prescribed pain medications, had not been addressed and sometimes there were discrepancies in the information and instructions provided by different healthcare professionals.

The participants stressed the importance of competent nurses providing realistic, relevant and helpful information that was tailored to

their individual needs and that the nurses should be open to questions and discussion. The face-to-face education was also dependent on their own cognitive capability to participate in the education and the time healthcare professionals had available to educate. Therefore, face-to-face education did not always support learning; participants said that what was discussed was sometimes easily forgotten or they forgot to ask what they had planned to ask beforehand.

In the study with patients undergoing knee arthroplasty (I), the contact and sufficiency of information provided face-to-face by nurses and physicians during hospitalisation were reported to be high (mean 3.54 ± 0.5), and explained 30% of the variance in the knowledge difference, as previously described.

Written material

Participants were familiar and content with the use of brochures (III) but only half (49%) of the participants in Study II had received information about their upcoming CRT treatment from brochures. The participants found brochures to be a useful and an attractive option because they were always available and easy to read, and focused on the patient's needs, although the layout and writing style were sometimes found to be boring and 'institutionalised'. Brochures could be referred to again and again, notes could be kept and the written information helped them to remember what to do and how. However, the information on pain management in the brochures, for example, was standardised and minimal and therefore reported not to be very helpful after discharge. Still, the brochures were trusted because the hospital published them (III).

Website

Using computer-based education after surgery in general received mixed responses from participants (III). For some participants the idea of using a website was appealing because they had plenty of time and could get assistance from the personnel while in hospital, while others felt they were too tired to use a computer and browse the Internet for information. However, participants acknowledged the attributes of websites as suitable for learning, as they may have updated information that was more specific than that found in the brochures (III).

The use of websites varied, and nine out of 13 participants had looked up information on the Internet related to their surgery (III) while a total of 18% (n=17) of the CRT patients (II) had used it as an information resource. A few participants (III) and some of their spouses had used YouTube videos demonstrating the upcoming surgery. Those who had searched on the Internet described how the plethora of information available there made it difficult for them to choose reliable sites and none of them had received any recommendations from healthcare professionals about good quality websites. Such recommendations were called for and without them participants tended to abstain from seeking information on the Internet (III).

Serious game

The idea of using a computer game to learn about pain management was met with mixed feelings by the participants and most of them ranked it last (III). Curiosity and interest but also lack of confidence, scepticism, prejudices and misunderstanding were the first reactions. Computer games also had some negative connotations with idleness and childishness. The participants did, however, express a willingness to try using such a game if

invited to do so at the hospital, given that they would have been assisted and taught how to do it.

Evaluation of the serious game

This section will report on the results from evaluation of the serious game developed to help patients learn about pain management (IV).

The findings from the interviews in Study III gave important information about the user perspective towards using a serious game in patient education. The participants in Study III were both sceptical and curious about the idea of using a game, indicating that a careful introduction was needed in implementation of such innovation. As described in the background, there is a need for more efficient patient education interventions⁵ and games have qualities which can support learning, according to adult learning theories.¹⁴ Therefore, the last study in this thesis was designed to develop and evaluate a serious game, intended to help patients learn about postoperative pain management. The game was evaluated in terms of usability and efficacy measured as improvement in knowledge after playing the game (IV).

Usability

It took the participants on average 34 minutes (range 24 - 45) to play one game session. The attributes of the game measured with AttrakDiff2 (possible scores -3 to +3) received scores above 0 in all dimensions. Attraction, which summarises the whole experience of software, received the highest score (mean 1.35 ± 0.78). The Pragmatic Quality, which is task-related and reflects usefulness and ease of use received a mean score of 1.23 (± 0.84). Hedonic Quality Identification, or how users identify with the

software in a social context received a score of 0.92 ($\pm$ 0.69) and Hedonic Quality Stimulation, which encourages development of the user's skills and knowledge received a score of 0.67 ($\pm$ 0.60).

Ease of use and usefulness as measured with the Post-Operative Pain Management Game Survey (possible scores 0-5) received median scores of 3.00-5.00 for all items except "I did not have any technical problems using the game" (Table 11). During testing (observation) 15 participants asked for help, each 1-5 times (median two times), most often because of technical problems such as the avatar freezing or getting stuck in walls or not being able to proceed from one game-day to another.

Usability was further explored with interviews where the participants confirmed ease of use. They found the game easy to play, and enough so to give to older people. All participants managed to go through the session with minimum assistance but the observation revealed that the people with good computer skills were quicker to grasp what to do and how (IV).

Table 11 Ease of use and usefulness of a serious game (N=20)*

	Median (IQR)	% of patients who fully agree
Ease of use		
I found it easy to learn to get the game to stop/start	5.00 (2.00)	55
It was fun using this simulation	4.00 (2.00)	30
The way information was presented on the screen was clear	4.00 (1.00)	15
It was easy to learn how to use the game	4.00 (1.75)	20
I found the activity easy to follow	4.00 (1.00)	5
The quality of video was good	3.00 (2.50)	25
I found the game easy to navigate	3.00 (1.75)	10
I did not have any technical problems using the game	2.00 (1.00)	15
Usefulness		
If I had recently had surgery or was preparing for one and the postoperative period, it would be helpful to get feedback from an expert on my pain management	5.00 (0.00)	85
I think the game would be a useful addition to other education about pain management	5.00 (1.00)	55
I think a simulation like this might encourage people who are recovering from surgery to learn about pain management	5.00 (1.00)	60
If I was recovering from surgery, I think the game would encourage me to learn about pain management	4.00 (1.00)	35

*Post-Operative Pain Management Game Survey (POP-MGS). Score 0-5.

Abbreviations: IQR, Inter Quartile Range

Knowledge about pain management

From the questionnaire PAK-PPM the number of correct answers from the participants increased, from 54% correct answers before playing the game, to 71% immediately after playing the game ($p=0.001$). Eighteen of the 20

participants improved their scores, the score for one decreased and one stayed the same. In 11 out of 15 questions the number of correct answers increased after playing the game. The number of correct answers increased most in items about pain medications and dosages. A smaller increase in number of correct answers was found in items about postoperative pain and management strategies. In the item about seeking help in case of signs of complications the number of correct answers decreased.

The efficacy of the game in terms of knowledge acquisition was explored in the interviews which were conducted after the participants played the game. A total of 16 participants said they had learned something new and four did not learn anything new because they said they already had the knowledge after having experienced surgery and/or using pain medication in the past. Participants (n=9) said that one of the most important lessons learned was the importance of taking medications regularly instead of waiting for the pain to become intolerable, as they sometimes did in real situations. Other important topics were learning about the effects and side-effects of different medications, and how to use multimodal pharmacologic and non-pharmacologic approaches.

The participants also confirmed our theoretical assumption that they used previous knowledge, and their own experience and life-situation while learning with the help of the game.

DISCUSSION

In this thesis, different perspectives of patients as learners have been explored. Patients' self-defined knowledge expectations and perceptions about different learning methods as well as an evaluation of a serious game for educational purposes have provided knowledge and new ideas about how patient education can be improved to better meet the needs of patients undergoing surgery.

The thesis has shown that not only patients scheduled for surgery but also people who visualise themselves having future surgery have very high knowledge expectations and want to be involved in their care by gaining knowledge. They express trust that healthcare professionals will provide them with sufficient knowledge using traditional educational methods such as face-to-face education and written material published by the hospital. They are open to using novel methods to learn as patients, given that healthcare professionals recommend such a method and help patients to use it. The idea of using a serious game to learn about common postoperative complications, e.g. pain management, was met with mixed feelings, both curiosity and interest as well as scepticism but the participants who evaluated such a game were positive towards its potential. The game helped them learn about different types of medication and to address common misconceptions and barriers to effective pain management.

Knowledge expectations

Participants expressed high knowledge expectations and these were similar between the different groups of participants. The highest knowledge expectations concerned bio-physiological issues, i.e. the disease, its

treatment and possible complications and functional issues, on how the disease and treatment may affect activities of daily life. Included in these expectations were also learning about one's own responsibility for the success of care and how to prevent complications. High knowledge expectations reflect signs of empowerment, as participants show willingness to learn about how to participate in one's own care and take responsibility for self-care. Similar high knowledge expectations have been reported in previous studies on different surgical populations^{32,33,38,135} and in the parent study of Study I on hip and knee arthroplasty patients in seven European countries.¹⁰⁵ There is therefore a growing body of evidence that surgical patients have both high and similar knowledge expectations in common, regardless of their type of surgery.

Although the interest of patients in learning about possible complications has been recognised before^{33,135} the readiness participants in this thesis expressed to learn about postoperative complications is an interesting result. Providing risk information is a sensitive issue and raises an ethical challenge for healthcare professionals but their attitudes have changed in the last decades. Similar to patient education in general, where there has been a shift from authority to shared decision-making¹⁰ healthcare professionals have moved from the paternalistic attitude that patients should be spared the distress that risk information may awake. However, previous studies have reported unfulfilled expectations of patients for information on possible complications. For example, in a recent study in 160 cardiac patients, over 80% wanted to learn about 'cardiac blues' after a cardiac event but only a minority did receive such information.¹³⁶ Another study reported that cardiac surgery patients became dissatisfied when they did not receive information about possible complications and when complications arose they thought these were caused by maltreatment rather than other more plausible reasons.^{44,137} Pain

is an expected and common postoperative complication and the high prevalence and severity of postoperative pain¹³⁸ is a cause of concern. The participants in Study III described insufficient education and knowledge about pain medication and management after surgery, supporting the notion that improvements in patient education on pain management, including addressing patient attitudes are imperative. Recent guidelines on postoperative pain management confirm this.⁴⁹ It can therefore be assumed that providing patients with risk information in relation to surgery, and information on how they can help to prevent or recognise possible complications timely may both support their empowerment and self-care. Risk information is therefore a field within patient education which nurses could pay more attention to and develop further in the future.

The knowledge expectations of patients with OA and HF were higher in older patients compared to younger patients, specifically on ethical, social and financial issues. Such a trend has previously been reported³² and is in line with the results from the larger sample of orthopaedic patients of which Study I is part.¹⁰⁵ Conversely, in a study on the relationship between learning needs and demographics of cardiac surgery patients, older patients were found to have fewer learning needs than younger people.¹³⁵ The result that older patients had higher knowledge expectations may be due to the possibility that younger people had already searched for and found health information on the Internet. Another explanation for the higher knowledge expectations in older patients might be that older people need more knowledge because their health is of more importance and concern than for younger people who have additional work and family responsibilities. It is recognised that the elderly have different learning needs from younger people as they are facing unique challenges, i.e., biopsychosocial issues due to frailty, increased vulnerability to depression,

anxiety and cognitive impairment and social isolation.¹³⁹ The elderly are therefore more likely to need social support and have financial concerns due to age-related declining health, and may find the ethical issues of more relevance as their end of life approaches and healthcare contacts increase. Within critical theory it has been argued that the most important aspect of educational gerogogy, i.e. the strategies involved in teaching and facilitating learning among older adults, is to empower older adults through education to affect policy changes regarding their age cohort such as those concerning health insurance, advanced directives, retirement and social security.¹³⁹

Knowledge expectations on financial issues related to having surgery were least fulfilled in this study, which is of interest for several reasons. The burden of out-of-pocket payments with expenditure borne directly by patients is increasing, according to the Organisation for Economic Co-operation and Development (OECD) and is approaching 20% in many countries.¹⁴⁰ For many patients, these expenditures may not be expected, and in order to meet their knowledge needs and support their empowerment they need to be informed and guided to resources such as websites where they can access relevant information. Subsequently, healthcare professionals need to have the basic knowledge about the social security system in their country, what out-of-pocket costs patients can expect, and where and how they may be compensated for such costs. They also need to familiarise themselves with available relevant and helpful web-based resources which they can recommend to patients.

Knowledge expectations were less fulfilled for patients with OA who had previous work experience within healthcare, patients with high information preferences, and women. These results confirm the notion that patient education has to be individualised and healthcare professionals must assess each person's knowledge expectations and

include them in the teaching plan in order to meet patients' learning needs.¹⁴¹ Such individualised, person-or patient-centred care is increasingly being emphasised by researchers, opinion-leaders, policy-makers and the nursing community^{20,142,143} in order to support patients' empowerment and self-care and improve outcomes of healthcare.

Empowering patient education emphasises that knowledge is the basic element of empowerment and when patients' knowledge expectations have been fulfilled, patients have a stronger potential for empowerment.³⁰ The results of this thesis confirm that patients expect multi-dimensional knowledge which is only partly fulfilled and that individualisation of the education is required. Improvements in patient education which take these results into account could support patients in gaining more empowerment, according to the theory.

Use and perceptions of different learning methods

In this thesis three available methods of learning were addressed: face-to-face education and the use of printed written material or websites, as well as the use of a serious game, though this could only be hypothetically explored.

Patients preferred the traditional and familiar methods of face-to-face education and written material to learn about pain-management after surgery, although they recognised their limitations. Their perceptions about traditional and novel methods were determined by trust in the information source and their own motivation to learn in the perioperative period. They were willing to try new learning methods, given the necessary support and assurance of their appropriateness by healthcare professionals.

Trust is fundamental in healthcare and involves both confidence and dependence in relationships for example between professionals and

patients.¹⁴⁴ In this thesis, contact and information from nurses and doctors during hospitalisation, was found to be an important factor in explaining the fulfilment of knowledge expectations of OA patients having knee surgery. Similar results were found for OA patients having hip replacement surgery, in the same study of which Study I is part of.⁴¹ HF patients who received information from staff at the cardiac outpatient clinic had fewer knowledge expectations than HF patients who did not receive information at the clinic. It is well known that face-to-face education is valuable to patients but its effectiveness has not been confirmed in quantitative studies.⁶² Face-to-face education has, however, the advantage of being an easily available method which can be used effectively when “teachable moments” occur when the patient demonstrates a readiness to learn² and is highly trusted by patients.¹⁴⁵ Trust is known to be a significant predictor of individuals’ online health activities¹⁴⁶ and the less patient-centred communication with providers is, the more likely people are to use websites for health information. With this perceived trust in healthcare professionals it is therefore of concern that nurses and physicians have reported themselves as lacking adequate patient educational skills and resources.¹⁴⁷ They have also reported insufficient knowledge about important patient-related factors such as post-treatment conditions, impact of illness on patients’ daily lives and how to support patients in self-care.¹⁴⁷ The training of healthcare professionals to acquire skills to optimise patient education is therefore required.¹⁰

Written material was described to be a trusted resource in this thesis, because the material was published or authorized by the hospital. On the other hand, it was not always perceived as a useful for pain management after discharge. Written educational material for patients, whether delivered printed or on websites has the common drawback of being

written at relatively high levels of reading ability, and far above the recommended levels.¹⁴⁸ Such a high level requirement of understanding has implications for people with limited health literacy¹⁴⁹ which has been described as applying to almost 50% of the public.^{150,151} Recommended strategies for people with low health literacy, besides using a reduced reading level of writing material, is to use videos as an adjunct to verbal narratives to increase understanding, as well as illustrated narratives with personal or third-person stories with corresponding illustrations.¹⁵² Interactive websites are an ideal vehicle for such strategies and are increasingly being developed for patient educational purposes. However, only a few participants in this thesis had used the Internet as an information source. They described how their impaired cognition in the perioperative period was a hindering factor in using the Internet when they did not know where to search for information and they called for advice and recommendations from healthcare professionals on reliable and good quality websites. Similar results were found in a sample of patients preparing for surgery, where less than half of the patients used the Internet to look for information. Those who did not use the Internet were receptive to being directed to specific websites.¹⁵³ More elderly people will be using the Internet when they gradually bring the computer skills acquired at work into retirement with them,¹⁵⁴ although currently 74% of global Internet users who are 15 years and older are younger than 45 years old.¹⁵⁵

These results on the use and perception of patients about different learning methods support the notion that the challenges for future patient education are the training of both patients and health professionals and the application of e-Health techniques to patient education.¹⁰

Use of serious games in patient education

The potential for using serious games in patient education was explored in this thesis. Such potential can be assessed based on the acceptance of patients and healthcare professionals, the efficacy of the method on learning, and on the pragmatic aspects of implementing games into healthcare.

Even though the study participants were sceptical about the idea of using a game, and had difficulty visualising them in the proposed situation, they were also interested and curious. The participants who evaluated the game were positive and rated the usability high. Testing in the design process of new healthcare games indicates that study participants with healthcare issues are receptive to the idea of using games, but usability issues can be a major concern.¹⁵⁶ Patient acceptance of consumer health information technology depends on a variety of factors such as device usability, training on how to use the device, computer skills and self-efficacy, environmental and organisational factors. These factors are important to consider when implementing new technology with patients.¹⁵⁷ Positive results were reported in an intervention study, using a combination of mobile (iPad) and personalised content management systems for educational purposes in older patients. There, neither age, major surgery nor hospitalisation were found to be significant barriers to the effectiveness of the intervention even though many patients were unfamiliar with the technology.¹⁵⁸ Based on the findings from the interview study (III) it can be assumed that it is very important to present new technology like a serious game as a part of patients' preparation for surgery, preferably before admission, when patient's motivation is unaffected by impaired cognition. To address any scepticism and prejudgment that patients may have towards serious games, careful introduction is needed. It is also clear that patients can only be invited to

use a serious game for learning because a fundamental characteristic of playing a game is voluntary participation⁷¹ and no one can be compelled to play a game. Participants rated the fun aspect of the serious game rather highly in the evaluation, which was an encouraging result and indicates that the game might appeal to patients.

The efficacy of educational interventions on outcome is obviously the most important issue in the implementation of innovative interventions. The participants who evaluated the serious game gained knowledge about pain medication and pain management strategies after playing the game. However, results need to be interpreted with caution due to the small sample size. Knowledge acquisition is the most common outcome measured in serious games in general,¹⁵⁹ and studies have shown beneficial effects in such games within healthcare.¹⁶⁰ The results of the game evaluation add to that evidence.

To date, very few evaluation studies have been published in this new field within patient education and more robust research is needed on the efficacy of games in general.¹⁶¹ However, there has been a call for more advanced use of games focusing on affective, motivational and physiological outcomes and behaviour change outcomes in general to improve health-related outcomes.^{159,160} Theoretically, and based on learning theories, games have the potentials to be effective tools in learning through their motivating qualities and the possibilities they offer for using reflection, similar to what is intended with the game on pain management. Through debriefing with a healthcare professional, the best aspects of both methods, face-to-face education and interactive game playing, are combined in what could be an optimal setting for patient education. A serious game could be helpful for people with low literacy as regards including health literacy skills and language barriers, since written text does not have to play a significant role in its presentation. The results from

the evaluation of the game confirmed several theoretical assumptions from different learning theories.²¹ Knowledge was acquired by receiving immediate feedback on actions which either resulted in positive or negative effects on the character's pain (behavioural learning), and the game helped participants remember facts about pain medication (cognitive learning). Participants used their previous and new experience (in playing the game) to construct new knowledge (constructivist learning), for example about the importance of taking pain medication regularly.

Finally, the pragmatic aspects of implementing games into healthcare need to be considered. The development of the game in collaboration with computer scientists was successful and the time it took to make the first version ready for evaluation was acceptable. The main cost of development lies in human resources but was not directly calculated here. Although the results of the evaluation are promising, several issues need to be considered. There are practical issues such as providing and maintaining tablet computers, and fitting their use into the busy hospital environment. There are issues around ownership and who should be responsible for maintaining and updating the game when needed. It is also necessary to determine what timing is best to introduce a game to patients preparing for surgery, whether the game should be available on the Internet or only used under the supervision of healthcare professionals and subsequently, what role the debriefing plays and whether the game can be useful without it.

Methodological considerations

The four studies in this thesis were designed and conducted carefully; however, several methodological considerations need to be addressed which have an impact on the studies' overall quality. They include limitations in the validity, reliability, trustworthiness and generalisability of the research findings.

Internal validity in quantitative studies refers to the confidence with which one can make statements about relationships between variables, and it is a process established in the design of the study.¹⁶² External validity is a function of the researcher and the design of the research¹⁶² to ensure the representativeness of the sample and thus provide the basis for generalisability to the target populations. The trustworthiness of qualitative studies can be assessed by their credibility, transferability, confirmability and dependability.¹⁶³ Credibility refers to confidence in the truth of the data and interpretations of them while reliability and dependability refer to the stability of data over time and condition.¹⁰⁴

Validity, reliability and trustworthiness

Internal validity in the quantitative studies was enhanced by using valid and reliable instruments for data collection whenever possible. Consequently, the use of non-validated instruments is a limiting factor. Several instruments had not been used before in the participating countries and needed to be translated. Others needed both translation and/or adjustment for the purpose of the studies, and as no instrument was available which fitted the content of the serious game the researchers decided to develop one (IV). Full psychometric evaluation was therefore not available for all the instruments as would have been optimal since they were being used in new patient populations and/or languages. The

instruments used in the studies in general had good internal consistency. An exception to the overall satisfactory internal consistency was the rather low Cronbach's α for the KHOS subscales (0.50 and 0.65), lower than has been reported earlier.^{36,115} This may have been due to the diversity of the three languages and translations of the instrument. Face validity was established for the new instrument, PAK-PPM, and it was useful in detecting changes in knowledge and had acceptable internal consistency. However, it needs to be validated further as it lacks established content and construct validity and test-retest assessment of reliability. Furthermore, the results of the study (IV) are based on pre-post testing where the post testing was done straight after playing the game. Responses may have been based on immediate memory recall rather than embedded or retained knowledge.

The translation of instruments followed established steps of forward-back translation,¹⁰⁴ performed by a group of nurse researchers, native speakers and professional translators. While all measures were taken to follow the translation process similarly in all countries and adhere to recommended practices including pretesting with a small sample of people¹⁰⁴ some cultural differences and nuances in the choices of words may have caused different understanding of the scales' questions. Three instruments were adjusted before use in the thesis. The adjustment consisted of changing the wording in few items to fit them to the target group of individuals scheduled for surgery (BQ-II, PRP) and to the serious game about pain management (POP-MGS).

In Study III, credibility was established by recruiting participants in the study who had the ability and willingness to share their experiences and perceptions on the subject under study and who had different backgrounds and experiences. The recruitment of participants continued until no new or relevant data emerged. This was established after the

preliminary analysis of 11 interviews and the findings were further confirmed after having recruited two more participants. The vignette was used because it was assumed that participants were not familiar with serious games on healthcare issues but not all participants immediately understood the idea of using a game to learn about pain management and this may have affected their responses and subsequently the quality of the data. Confirmability was established by presenting the audit trail of the study, describing the course of development of the completed analysis. Through a detailed description of the data analysis and structure of the categories with confirmation by three authors, the dependability of the research findings was established.

In Study IV the interviews were conducted to validate findings from the survey which participants had responded to immediately before. They were short and conducted at the end of the 60-90 minute-long data collection; therefore, the participants may have been tired or anxious to finish their contribution and less willing to discuss and reflect on their experience.

Selection bias was considered as a threat to internal validity (I - II) because of the inclusion criteria of non-cognitive impairment and the large number of non-responders. To select patients without cognitive impairment may have been difficult because the nurses only had patient records to rely on. This may have caused unintentional inclusion of patients with cognitive impairment, if it was not documented in their records, possibly leading to non-responses from those individuals. It may also have led to exclusion of people who might have been competent to participate in spite of documented cognitive impairment. The decision to exclude people with cognitive impairment can be debated based on how common the condition is in the elderly. However, other methods than self-

reported surveys may be better suited to collecting data from this patient population.

Data collection over a long time (two years) helped to prevent potential bias caused by seasonal fluctuations in hospital practice (I - II) thus affecting external (temporal) validity.

Statistical conclusion validity contributes to internal validity and shows inferences made about cause and effect variables based on statistical evidence.¹⁶² Statistical analysis methods were chosen based on sample size, distribution and level of the data.¹⁶⁴ One consideration was the use of parametric or non-parametric tests. The validity of parametric tests is based on the assumption that data are normally distributed, but large sample sizes allow for exception to this rule.¹⁶⁴ In Study II the cut-off point for defining high and low knowledge expectations (KE) was decided to be the median value of the data, which was heavily skewed. This decision can be debated; however, choosing quartiles instead, which was another option, would have resulted in reduced sample size and loss of power.

Sample and research design

Several strategies, specifically in the sampling plan and study design, can be applied to enhance the external validity of research. Acceptable sample size and the use of probability sampling supports the external validity, and the use of multiple sites reduces the risk that findings are only relevant to the specific setting (I - II).

The response rate was rather low in both studies I and II or just above 50% whereas a response rate above 65% is considered sufficient for most purposes.¹⁰⁴ However, nonresponse rates have not been found to be a valid or reliable indicator of nonresponse bias in survey research and instead scientists have suggested conducting nonresponse bias analysis.¹⁶⁵ For Study II, analysis of those who participated and did not participate in the

study revealed no significant difference. The age and proportion of men and women corresponded well with the 'typical' European CRT recipient who is a 70-year-old male (73%).¹⁶⁶ The low response rate among patients with HF (II) may be due to their poor health status as is well known in this patient population. Also, in some instances hospital logistics may have influenced the response rate as questionnaires were sent out to patients just a few days before hospital admission, giving them a very short time to consider whether to participate and answer the questionnaire.

Attrition bias can threaten external validity in follow-up studies and occurs when a particular category of respondent does not complete the study. This was true for Study I with a 23% dropout between time points 1 and 2. A follow-up analysis between respondents and non-respondents after surgery (time-point 2) revealed no difference between the two groups in regard to common background characteristics. The sample was similar to the patient population undergoing knee arthroplasty in Sweden in terms of mean age (67 vs 69) and proportion of men and women (47/52 vs 43/57) respectively.¹⁶⁷ It is likely that some dropout of patients can be explained by postoperative complications. Another reason may be that patients had a narrow time-slot to answer the second questionnaire before they went home. As this time at discharge is stressful for many, they may have either forgotten or chosen not to fill out and return the second questionnaire.

The multi-centre design minimised the bias which can occur in a single site study (I - II).¹⁰⁴ The inclusion of all Icelandic hospitals which perform knee arthroplasty ensured the representativeness for Iceland, while the Finnish and Swedish hospitals were not chosen randomly but by convenience (I). Similarly, the five out of 30 Swedish hospitals which perform CRT pacemaker implantation were chosen by convenience (II).

International collaboration on research projects is being encouraged in the globalized world and has several benefits but also challenges.¹⁶⁸

Different settings may call for adjustments of the research plan, project management can be very complex, and communication is of paramount importance in order to prevent misunderstanding and mistakes at all stages of the data collection.¹⁶⁹ The importance has also been stressed of strong relationships among members, where face-to-face dialogue plays an important role, of clear aims of the partnership, and of the complementary capacities of the collaborators.¹⁶⁸ This description conforms with the experience of conducting the two international studies (I - II) in this thesis.

The three included countries, Iceland, Sweden and Finland share similar healthcare systems and hospital services. Study I was a part of a larger research project. A detailed research protocol was shared with all research participants in each country, and regular meetings (both face-to-face and teleconferences) and a shared Internet site (Moodle) were used to share project milestones and deliverables and address potential problems in patient recruitment and data handling. In Study II the research group visited each centre in Sweden and introduced the study and distributed and discussed the detailed research protocol and code-book in order to coordinate the data collection logistics. A study nurse was employed in Sweden to coordinate data collection, update the researchers and keep regular contact with the nurses in the other centres who were responsible for data collection. Lessons learned include the importance of having a detailed research protocol while simultaneously allowing for necessary flexibility, and providing sufficient time for all centres to prepare for their participation. Regular contact and personal communication facilitated the data collection and ensured that it went smoothly.

Generalisation

Generalisation is the process of using data to infer a general statement that has applicability to other people, setting or time.¹⁶² It is the function of

both the researcher and the user of the knowledge or the research findings. Generalisation can be made to the study population or across populations, where it includes applying findings to populations, settings or times not represented in the sample.

Generalisability is the goal of quantitative research but not qualitative research, although qualitative researchers have begun to note the importance of addressing generalisation to ensure that insights from qualitative inquiry are recognised as important sources of evidence for practice.¹⁷⁰ There are three different models of generalisation: the classic statistical generalisation model, analytic generalisation, and the case-to-case transfer model (transferability).¹⁷⁰

In the quantitative studies in this thesis, low response rate (I - II) and attrition (I) were of concern but analysis of non-respondents did not detect any significant differences in the sample characteristics. Furthermore, the multi-centre design, supported the generalisability of the findings to the study populations, particularly for Iceland (I).

Replication of studies enhances the potential for generalisability.¹⁷⁰ The results on knowledge expectations of surgical patients (I - II) confirm results from previous studies which used the same instrument in different populations of surgical patients. They indicate similar rankings for knowledge expectations and their fulfilment between subscales although the results about relationships with background factors are more inconclusive. There is therefore a growing evidence on the knowledge expectations of surgical patients and their fulfilment but interpretability of the results is lacking. Establishing 'interpretability' involves making changes in outcomes meaningful¹⁷¹ and identifying the minimum important difference that has some clinical significance. Such evaluation is needed in the future¹⁶⁹ for the utilisation of these results within practice.¹⁶²

The case-to-case transfer model of generalisation or transferability of the findings from Study III was supported by a clear description of the selection of the participants and the context, data collection and process of analysis. A thorough description of the participants was purposefully withheld for confidential reasons to avoid their recognition in the small Icelandic society, although this might have affected transferability. The findings on perceptions about available methods (face-to-face education, written material and websites) were confirmed by previous studies, which increases confirmability and transferability, but the participants' thoughts about serious games need further confirmation.

Study IV was an evaluation study with purposeful sample of non-patients and small sample size. The results of the evaluation are limited to the subject (pain management) and the homogenous cultural context and therefore cannot be generalised.

Research implications

This thesis has explored different aspects of the patient as a learner and has provided several new ideas for future research. It has been established that the knowledge expectations of surgical patients are high and multi-dimensional. It would be interesting to explore further how those expectations are formed, and how patients rate the importance of their knowledge expectations compared to the level of their expectations as was measured in this thesis. It is also of interest to study the relationship between fulfilment of knowledge expectations and background factors such as health literacy or culture as well as outcome measures such as postoperative pain, or postoperative self-care during recovery.

Study III provided insight into the situation of surgical patients during the postoperative period and their reflections on different methods to learn about pain management. It would be interesting to develop an intervention study evaluating the effect of specially trained nurses providing structured face-to-face patient education to surgical patients. There is also a need for an instrument which can assist healthcare professionals to evaluate the quality of websites so they can recommend them to patients.

The evaluation of the serious game provided several research ideas. After some further development the game should be tested in a real hospital environment with surgical patients and trained nurses. It would be interesting to assess the longitudinal effect of the education, for example its effect on pain prevalence and severity, and to compare groups of patients with high and low literacy. The instrument developed for the study to assess knowledge of patients on pain management needs to be further developed for more general use and validated.

Clinical implications

This thesis has presented how the knowledge expectations of different groups of people, preparing for surgery, are both high and similar, and how those expectations are not being fulfilled. Both patient-related and organisational factors, such as access to knowledge within the hospital, were associated with knowledge expectations and their fulfilment. Healthcare professionals can use the findings to restructure the content of patient education, paying special attention to providing education on self-care in relation to potential postoperative complications, pain management, and the financial impact of undergoing surgery. They should also consider reorganising the practice of patient education within the hospital in order to meet the individual knowledge needs of patients.

The findings on participants' use and perception of different learning methods challenge healthcare professionals to improve their own communication and educational skills, ensure that sufficient time is provided for patient education within the busy hospital environment and consider health literacy when developing educational material. They also need to familiarise themselves with the relevant and available websites for their patients and other web-based applications, which can be useful for patient learning. More detailed strategies are proposed in Study III.

A serious game was found to have the potential to help patients learn about pain management after surgery and it was appreciated by the users. These findings can be used by hospital managers who are responsible for the development of hospital services such as patient education, and by funding agencies. The findings can also support future development and more robust testing of serious games within healthcare.

CONCLUSION

People preparing for different types of surgery have high and similar knowledge expectations and older people have more expectations than younger people. Communication with healthcare professionals during hospitalisation is a major contributor to the fulfilment of knowledge expectations. Healthcare professionals can improve patient education practices by focusing on individual concerns during face-to-face education, addressing possible complications of surgery and how patients can participate in their prevention, and providing patients with knowledge on financial issues relevant for their surgery.

When incorporating new educational strategies such as serious games or websites into practice, healthcare professionals need to present those strategies carefully to patients and consider their cognition state.

A serious game has potential to help people learn about postoperative pain management and improve their knowledge, skills and attitudes when used in combination with face-to-face education provided by healthcare professionals.

SVENSK SAMMANFATTNING

Patienter som ska genomgå kirurgiska ingrepp behöver kunskap för att kunna medverka till sin vård och utföra egenvård under den postoperativa perioden. Patientutbildning underlättar sådan kunskapsinhämtning och flera metoder kan användas för detta, till exempel personliga möten, broschyrer eller användandet av informationsteknik; såsom webbplats eller datorspel. Sjukvårdspersonal har dock inte varit så aktiva att tillvarata de möjligheter som informationstekniken har att erbjuda inom området, inklusive användandet av s.k. seriösa spel (eng. serious games). För att kunna organisera patientutbildning som uppfyller patienternas behov och önskemål behövs mer kunskap om vad dessa uppfattar sig behöva veta i förhållande till sin kommande operation och vad de anser om idén att använda ett seriöst spel för att lära sig om egenvård.

Det övergripande syftet med avhandlingen var att beskriva kirurgpatienters kunskapsförväntningar, hur kirurgpatienter vill lära sig och att undersöka möjligheten att använda seriösa spel i patientutbildning.

Avhandlingen omfattar fyra studier som använt både kvantitativa och kvalitativa data för att beskriva olika aspekter av patientens inläring i förhållande till sin operation. Studie I har en prospektiv och jämförande design baserad på enkätdata från 290 patienter med artros vilka genomgått knäledsplastik. Enkätdata insamlades före operationen samt före utskrivning från sjukhus. Data insamlades med avseende på uppfyllandet av kunskapsförväntningar och relaterade faktorer. Studie II är en tvärsnittsstudie som inkluderade 104 patienter med hjärtsvikt som skulle genomgå en planerad operation för implantering av en biventrikulär pacemaker (s.k. CRT). Data insamlades med avseende på kunskapsförväntningar och relaterade faktorer. I Studie III undersöktes 13 kirurgiska patienters uppfattningar av nya och traditionella metoder för

inlärning om postoperativ smärtbehandling. Patienterna deltog i en kvalitativ intervjustudie som senare analyserades med hjälp av innehållsanalys. Studie IV beskriver utveckling och utvärdering av ett seriöst spel som syftar till att deltagaren/spelaren ska lära sig om smärtlindring. I studien deltog 20 personer, som rekryterats från allmänheten. Spelet har utvecklats av en tvärvetenskaplig grupp efter ett strukturerat tillvägagångssätt. Uppgifter om spelets effektivitet och användbarhet insamlades i en session med enkäter, observationer och intervjuer.

Deltagarna rapporterade höga kunskapsförväntningar. Förväntningarna var högst inom området kunskap gällande sjukdom, behandling och komplikationer samt den funktionella betydelsen av hur dagliga aktiviteter påverkas, vilka båda innefattar egenvårdsmoment. De flesta deltagare ville få kunskap om möjliga komplikationer i samband med operationen. Inget av dessa kunskapsmoment infriades av förväntningarna. Deltagarna erhöll mest kunskap om fysiska och funktionella frågeställningar och minst om de finansiella och sociala aspekter som rörde deras sjukdom. Den viktigaste prediktorn för uppfyllandet av kunskapsförväntningar var tillgång till kunskap hos läkare och sjuksköterskor på sjukhusen. Förtroendet för informationskällan och egen motivation att lära formade hur deltagarna tänkte angående olika inlärningsmetoder. Även om deltagarna var öppna för att använda nya inlärningsmetoder, såsom webbplatser eller spel, var de också tveksamma till deras användning, och istället efterfrågades information av sjukvårdspersonal.

I utvecklingen av det seriösa spelet, togs hänsyn till tidigare forskning om patienters utbildningsbehov om smärtlindring. Likaså har teorier om egenvård och vuxenutbildning, samt olika spelprinciper varit användbara. Spelets huvudperson är en kirurgpatient nyss utskriven från sjukhuset, som

behöver sköta dagliga aktiviteter och samtidigt hantera sin postoperativa smärta med hjälp av olika strategier. Deltagare som utvärderade en första version av spelet förbättrade sina kunskaper och beskrev spelets användbarhet som hög. De var positiva till denna nya inlärningsmetod och fann den lämplig som inläring om smärtlindring efter operation, trots att metoden uppvisade vissa tekniska begränsningar.

Patienter som ska genomgå kirurgi har höga kunskapsförväntningar avseende alla aspekter av deras kommande operation. Även om de föredrar direkt kommunikation med sjukvårdspersonal som en källa för kunskap, kan de vara öppna för att prova att använda flera nya metoder, såsom spel. Preliminära resultat visar att ett seriöst spel kan hjälpa individer att lära sig om smärtlindring, och har en potential att förbättra patienters kunskaper. För att genomföra denna nya patientutbildningsmetod behövs en noggrann introduktion samt rekommendation och stöd från hälso- och sjukvårdspersonal.

Nyckelord: kirurgpatienter, kunskapsförväntningar, lärande, seriösa spel, utbildning

ÁGRIP Á ÍSLENSKU

Fræðsla gerir sjúklingum betur kleift að taka þátt í umönnun sinni sem er mikilvægt fyrir bata eftir skurðaðgerð. Sjúklingafræðslu má veita með ýmsum aðferðum, til dæmis munnlega, með bæklingum eða með því að nota upplýsingatækni á formi vefsíðna eða kennslutölvuleikja. Heilbrigðisstarfsfólk hefur verið lengi að tileinka sér möguleika upplýsingatækninnar í sjúklingafræðslu, þar með talið notkun kennslutölvuleikja. Þörf er á meiri þekkingu um fræðsluþarfir skurðsjúklinga en jafnframt um viðhorf sjúklinga til nýrra námsaðferða. Kennslutölvuleikir eru ein leið sem gæti gagnast sjúklingum en notagildi þeirra hefur lítið verið rannsakað.

Meginmarkmið þessarar ritgerðar var að lýsa væntingum skurðsjúklinga til fræðslu, lýsa því hvernig þeir vilja læra og að kanna möguleika kennslutölvuleikja í sjúklingafræðslu.

Ritgerðin samanstendur af fjórum rannsóknargreinum. Notuð voru meginleg og eigindleg rannsóknargögn til að lýsa ýmsum hliðum náms einstaklinga sem fara í skurðaðgerð. Rannsókn I er framsýn samanburðarrannsókn sem gerð var á 290 sjúklingum með slitgigt sem gengust undir hnéliðskipti. Gögnum var safnað með spurningalistum fyrir skurðaðgerð og fyrir útskrift af sjúkrahúsi um uppfyllingu væntinga til fræðslu og tengda þætti. Rannsókn II er þversniðsrannsókn með þátttöku 104 sjúklinga með hjartabilun sem voru á leið í aðgerð til að fá ígræddan sérstakan hjartagangráð (e. cardiac resynchronisation therapy (CRT)). Gögnum var safnað með spurningalistum, fyrir ígræðsluna, um væntingar til fræðslu og tengda þætti. Rannsókn III er eigindleg rannsókn með þátttöku 13 sjúklinga sem nýlega höfðu farið í liðskiptaaðgerð eða hjartaskurðaðgerð. Gögnum var safnað með viðtölum þar sem sjúklingar lýstu viðhorfum sínum til nýrra og hefðbundinna aðferða til að læra um

verkjameðferð eftir skurðaðgerð. Gögnin voru greind með innihaldsgreiningu. Rannsókn IV lýsir þróun og mati á kennslutölvuleik til að læra um verkjameðferð eftir skurðaðgerð, með þátttöku 20 sjálfbóðaliða. Leikurinn var þróaður af þverfaglegum hópi hjúkrunarfræðinga og tölvunarfræðinga. Gagnsemi og notagildi leiksins voru metin með spurningalistum, áhorfi og viðtölum.

Þátttakendur höfðu miklar væntingar til fræðslu. Væntingar voru mestar á sviði lífeðlisfræði um atriði er sneru að sjúkdómi, meðferð og fylgikvillum og á sviði færni um áhrif veikinda á daglegar athafnir. Bæði sviðin fela í sér atriði um sjálfsumönnun. Flestir þátttakendur vildu fá fræðslu um mögulega fylgikvilla skurðaðgerðar. Væntingar voru ekki uppfylltar á neinu þekkingarsviði þó best á sviði lífeðlisfræði og færni en síst er vörðuðu fjárhag og félagslegan stuðning í tengslum við veikindi. Væntingar voru best uppfylltar meðal þeirra sem höfðu góðan aðgang að fræðslu á spítalanum frá hjúkrunarfræðingum og læknum.

Viðhorf þátttakenda til mismunandi námsaðferða mótaðist af trausti á fræðslumiðli og eigin áhugahvöt. Þátttakendur voru opnir fyrir notkun nýjunga á borð við vefsíður og kennslutölvuleiki en jafnframt nokkuð tortryggirnir og töldu mikilvægt að fá ráðleggingar og aðstoð heilbrigðisstarfsfólks við slíka notkun.

Kenningar um sjálfsumönnun og nám fullorðinna, aðferðir leikjahönnunar og tiltæk þekking á fræðsluþörfum sjúklinga um verkjameðferð voru notaðar til grundvallar við hönnun kennslutölvuleiksins. Persóna leiksins er nýlega útskrifuð af sjúkrahúsi eftir skurðaðgerð og þarf að sinna daglegum athöfnum jafnframt því að meðhöndla verki sína. Þátttakendur rannsóknarinnar sem lögðu mat á kennsluleikinn bættu þekkingu sína og töldu nothæfni leiksins mikla. Þeir voru jákvæðir gagnvart þessari nýju námsaðferð og fannst hún henta vel til

að læra um verkjameðferð eftir skurðaðgerð þrátt fyrir nokkra tæknilega örðugleika.

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Lykilorð: Kennslutölvuleikur, nám, sjúklingafræðsla, skurðsjúklingar, væntingar til fræðslu

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